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Consumers and the social world of health care. Outsiders in the expert's world: A grounded theory study.

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STATEMENT OF CONTRIBUTION OF OTHERS

Nature of Assistance	**Contribution**
Fees and Stipend Support	Australian Postgraduate Award PhD Scholarship
Supervision	Professor Jane Mills 80% Professor Kim Usher 20%
Other Collaborations	Professor Amanda Kenny provided support through voluntarily facilitating the digital storytelling workshops in the data collection phase of this study.
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ABSTRACT

Background

Until the 1970s, the biomedical model was the predominant model of care used in Western health care system. Under this model, the human body and how it is affected by illness are central to treating patients, to the exclusion of peoples' experience of illness (Engel, 1977; Henderson & Henderson, 2010). Within this model, doctors dominate and patients are passive, obedient and admiring (Digby, 1997). The introduction of the biopsychosocial model of health care in the 1970s shifted focus from the human body and illness to consumers' psychological and social contexts being viewed in conjunction with their illness. Although the concept of patient-centred care was introduced in the mid 1950s (Balint, 1969; de Haes, 2006) it was not until the 1990s that it became prominent in Western health care policy and practice. The concept of patient-centred care emphasises care that is "respectful of and responsive to individual patient preferences, needs and values and ensur[es] that patient values guide all clinical decisions" (Committee on Quality of Health Care in America, 2001, p. 6). Under this model, there is an assumption that consumers share power and responsibility for their health and health care with health experts (Mead & Bower, 2000).

The interactional relationship between consumers and health experts is central to the delivery of health care. While 'doctor-patient' relationships still play a key role in health care, these relationships are not as haloed as they once were (Bury, 2004). The "golden age of doctoring" is over (McKinlay & Marceau, 2002, p. 379). Consumers' central health professional may now be a nurse practitioner or a complementary practitioner (McKinlay & Marceau, 2002). Gaining insight into processes of interaction between consumers and health experts across health settings and health conditions enables improvements in both efficiencies and quality of health care, and has the potential to improve consumer health outcomes.

Aim

The aim of this study is to construct a grounded theory that explains the processes of interaction between health consumers and health experts.

Justification

There is a gap in the literature that presents processes of interaction between consumers and health experts across a variety of health settings and health conditions.

Ethics

Ethical considerations were followed in accordance with the National Statement on Ethical Conduct in Human Research 2007 (The National Health and Medical Research Council, the Australian Research Council, & and the Australian Vice-Chancellors' Committee, 2014). The Far North Queensland Human Research Ethics Committee (FNQ HREC) approved the study (HREC/13/QCH/28–830) and James Cook University Human Ethics Research Committee endorsed the approval (H5173). Further to ethics approval, Site Specific Assessment (SSA) was required to conduct non-participant observation and to recruit study participants at the Cairns Hospital. Approval was granted (SSA/14/QCH/8 - #830).

Methodology

The researcher used Strauss and Corbin (Strauss & Corbin, 1990, 1998) and Corbin and Strauss’ (Corbin & Strauss, 2008) evolved version of grounded theory to examine the process of interactions between consumers and experts. This version of grounded theory is explicitly underpinned by symbolic interactionism. Grounded theory provides a systematic approach to conducting research, which aims to generate theory grounded in data. It is also an appropriate way to examine an area of study in which there is little prior knowledge. Symbolic interactionism provides a perspective through which to explore processes of action and interaction.

Methods

Essential grounded theory methods (Birks & Mills, 2011) used in this study include: concurrent data collection/generation and analysis, theoretical sampling, initial and intermediate coding of data, constant comparative analysis of data, theoretical integration of data, selecting a core category and memo writing. Data were collected and generated using the following techniques: demographic information questionnaires, semi-structured interviews, participants' diary entries, fieldnotes, non-participant observation and digital storytelling.

Sampling

The study was conducted in the Australian regional city of Cairns in Far North Queensland. The researcher used purposive and theoretical sampling techniques, which resulted in a total of 32 study participants, comprising 23 health consumers and 9 health experts.

Findings

The resultant product of this study is the grounded theory titled: *Outsiders in the experts' world*. The theory consists of five categories and their sub-categories, which explain the process experienced by people who unexpectedly enter the social world of health care and become health consumers. Consumers generally move sequentially through the stages of the process, although the stages may overlap or be revisited. The categories and sub-categories of the grounded theory are: 1) Unexpected entrance (Emotional fluctuations; Changing perceptions of self); 2) Learning a new role (Acquiring knowledge; Learning the language of health care; Confronting mortality; and Cultivating support); 3) Establishing a presence (Gaining confidence; Choosing a voice; and Establishing relationships; 4) Confronting the dichotomy of 'us and them'; 5) Tailored care (Listening and acting; and Accessing experts).

Discussion

Findings from this grounded theory study present the processes of what happens when a person enters the social world of health care and how processes of interaction between them and health experts play out. The contingent relationship between *what* and *how* provides the

basis for the discussion chapter, which addresses questions of *why* consumers are outsiders in the experts' world. The discussion chapter introduces extant theories to provide explanatory power to the grounded theory and to contextualise it within the broader literature.

Conclusion

Interactions between consumers and health experts are central to the delivery of health care. Findings from this study indicate that regardless of consumers' experience in their role, they remain outsiders in the social world of health care. The findings are significant in the current health care climate, which promotes consumer centred health care. A shared understanding between all stakeholders around the role of consumers will support the development of strategies to continually improve processes of interaction between consumers and health experts and to strengthen the consumer role.

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GLOSSARY OF TERMS

Term	Definition
Consumer	A person or a carer or family member of a person who, because of a diagnosed condition or undiagnosed symptoms, regularly interacts with health professionals (experts).
Data collection	Signifies the researcher as an *objective* instrument in collecting data *from* participants (Mills, Birks, & Hoare, 2014)
Data generation	Signifies the researcher is a *subjective* active participant in generating data *with* participants (Mills et al., 2014)
Disease	Clinical perspective of illness (Johna & Rahman, 2011)
Essential grounded theory methods	Refers to the set of methods, which when used together to generate theory, constitute a grounded theory (Birks & Mills, 2011)
Experts	The term 'expert' is used to signify all health professionals. Use of this term links to the title of the grounded theory.
Illness	"The innately human experience of symptoms and suffering" (Johna & Rahman, 2011)
Methodology	"A way of thinking about and studying social phenomena" (Corbin & Strauss, 2008, p. 1)
Methods	"Techniques and procedures for gathering and analysing data" (Corbin & Strauss, 2008, p. 1)

PROLOGUE

> *[…] the world is always different. Each morning we open our eyes upon a different universe. Our intelligence is occupied with continued adjustments to these differences. That is what makes the interest in life. We are advancing constantly into a new universe;[…]*
>
> *(Mead, 1936, p. 291)*

> *Discipline is freedom, but that is hard to believe when you are struggling and lose focus. To make something worthwhile there needs to be a challenge.*
>
> *(Weekes, 2014, p. 110)*

The PhD process has certainly opened my eyes to new universes: academia, research, health care, participants’ universes and my own personal ever-changing universe. The path to my PhD seems fairly straightforward - undergraduate degree, research grants, a post-graduate certificate in research studies and enrolment in a PhD program. My interest in research, however, began well before I embarked on an educational path. As I prepared my PhD confirmation seminar, distant memories surfaced that pointed to two distinct factors: my early questioning of quantitative research and the influence of a friend’s mother.

As a teenager and young adult in the late 1970s early 1980s I distinctly recall the reign of quantitative research. Quantitative findings from research studies were reported and discussed on radio and television news segments and on current affair programs. I recall many evenings of impassioned discussion with my father, after watching current affair programs such as the 7.30 Report or 60 Minutes on television. For me, quantitative research was too absolute. “How could people be reduced to numbers and statistics?” I asked. “What about people’s experiences and where were the *what*, *how* and *why* questions?” Back then, I had no notion of the terms ‘qualitative research’ and the ‘constructivist paradigm’. Now I can confidently state that I am instinctively and intrinsically a qualitative researcher within the constructivist paradigm.

The second factor that contributed to my interest in research occurred in my late teens when I lived with a childhood friend and her family for 18 months. My friend’s mother was a nurse and a mature age student. She seemed to be forever studying: completing an assignment, preparing for an exam, or undertaking a research project. The dining room table was her desk and it was forever strewn with textbooks. I was always interested in what she was doing and we would discuss her work. Her thirst for knowledge and learning inspired me. When I was selecting subjects for my final year at high school I chose subjects that would enable me entry into nursing as a career. Not because I had any particular yearning to be a nurse but because, at that time, for me nursing equated to study, learning, research and the acquisition of knowledge. I never did enrol in nursing and my life led me down many different paths, to many different countries and to a myriad of life experiences.

Stepping forward 20 odd years and many life experiences later I enrolled as a mature aged student in a Bachelor of Arts degree. Enrolling in an Arts degree was not a means to an end. I wanted and needed to use my brain studying topics that interested me. I chose to major in French and Environmental Studies. Not long after completing my degree in 2006 I was offered a position as the personal assistant to the Chief Executive Officer of a non-profit health organisation. As a non-clinician and as an infrequent user of mainstream health services, I had limited knowledge of the Australian health system. The position opened my eyes to a new universe.

In 2008 I began toying with the idea of returning to university and completing an Honours degree with the aim of then applying to a PhD program. I was interested in pursuing a career in health research, however I was hesitant to add to my higher education debts and to forgo a wage for 12 months. So in 2009 I applied for a novice researcher fellowship, through James Cook University-Primary Health Care Research, Evaluation and Development (PHCRED), to undertake a study about mental health nurses in Australian general practices. My application was initially rejected because I was not a health professional. I responded, pointing out that I worked in a health organisation that represented general practices and that my study proposal reflected performance indicators that the organisation was required to report against to government. My application was accepted.

The fellowship covered general study expenses and my wage for one day per week for a period of 12 months. The study achieved two things: 1) a publication (Jennifer Chamberlain-Salaun, Mills, & Park, 2011); and 2) a firm conviction that I wanted to pursue a career in health research. So in 2010 I enrolled and completed a Graduate Certificate in Research Methods in the James Cook University, School of Nursing, Midwifery & Nutrition and in 2012 I was accepted into the School's PhD program.

Choosing my substantive area of inquiry

Numerous factors influenced my choice of PhD study topic and methodology. In 2009 I attended a PHCRED conference as part of my research Fellowship. The final session of the conference was an open forum. The forum's panel included representatives from State and Federal health departments. The key point that I picked up on from the forum was that health care teams were a government priority and that, according to the government representatives, there was a lack of research being conducted around health care teams. Health care teams was the 'buzzword', including terms such as multidisciplinary and inter-professional used to describe them. I had my topic, or so I thought.

Once I began searching the literature it became evident that there was ample research around health care teams. Two factors, however, stood out for me in the literature: 1) the myriad of 'buzzwords' used to describe health care teams and their apparent non-systematic use; and 2) the general lack of consumers' perspectives in research relating to health care teams. In an attempt to make some sense of the terminology used to describe health care teams I undertook an integrative review of the literature, which is included in Chapter 2 of this thesis. During my foray into the literature I noticed that research that included the consumer perspective, generally categorised consumers according to their health condition or focused on particular health care settings. I wanted to look beyond people's health conditions and specific health settings and find out what processes were involved in consumers interacting with health care teams.

My interest in processes is influenced by my professional experience. For five years prior to commencing my PhD, I worked in non-government health organisations developing and implementing quality management systems and I am also a quality management systems auditor. For my PhD study, I was interested in researching processes rather than individuals' lived experiences, with the aim of developing a theory. This focus influenced my decision to use grounded theory methods to conduct my study. Grounded theory methods constitute a process of actions and interactions for conducting research, with the aim of developing a theory. With the assistance of my principal supervisor, I identified my PhD topic: The process of interaction between consumers and health care teams. I did not question whether the topic would sustain me for the three years duration of the PhD program; I felt sure that the process and the challenges would sustain me.

Very early in the process of generating data for this study it became evident that the concept of health care teams was generally non-existent among study participants. Rather, consumers considered that they were being cared for by individual professionals, who may or may not communicate with other health professionals involved in their care. I could well have pursued this aspect. But as is the case when using grounded theory methods, I was guided by codes and categories that I identified in the data and the concept of teams, or not, was minimal within the broader data. The focus of my topic became the process of interaction between consumers and health professionals, who I later referred to as 'experts'.

While reading Richardson & St. Pierre (2005) I was prompted to deeply consider the purpose of this research study. In my PhD proposal I stated that the purpose of my study was to "enable improved efficiencies in the quality of health care services [which…] has the potential to improve consumer health outcomes". This is a valid purpose that fits comfortably with the political agenda of spending less, whilst achieving more. Now, two years into my study, as I reflect more deeply on the purpose of my study I believe that its purpose is to generate thinking and discussion about the possibility of different relations and ways of interacting between consumers and experts that acknowledges and respects, above all, each persons humanness.

My position as researcher

Health professionals, both practicing and academics, undertake most of the published health related studies. I am not a health professional nor an academic (yet). I have no experience of interacting with consumers nor do I have a health condition that requires me to interact with health professionals on a regular basis. My interactions with health professionals are related to two key events in my life. I gave birth to my son in 2001, and was subsequently admitted to hospital on four occasions due to retained placenta. Then in 2008 my father was treated for prostate cancer. I accompanied him to appointments with specialist doctors' and his general practitioner, to his chemotherapy and radiation treatment sessions and liaised with a community care organisation to ensure that my father could access practical and health services at home. I then sat by his side for four days in a palliative care clinic until he died. These two temporary short-lived experiences provided me with some insight into what it means to be a consumer. I can only conceive of what it must mean to be an ongoing long-term consumer.

Writing the thesis

I have heard it said many times during my PhD candidature that only a handful of people will read a thesis: the student, their supervisors and the examiners. While this may well be true, I have attempted to present the PhD process and my grounded theory as clearly and as intelligibly as possible. Although academic publications have evolved beyond the stifled and complex scientific and academic writing styles of the early-mid 20th Century, all too many research reports and publications still remain accessible only to limited audiences. This defeats the purpose of research; research publications should be an 'easy read' so that access is not limited. Easy does not mean simple. In fact rendering concepts simply is perhaps more challenging than obscuring concepts in unnecessary vernacular that distances the reader.

In a writing workshop that I attended early in my PhD study the facilitator presented, what for her is the best piece of writing ever: the introduction of Nobel Laureate Elizabeth

Blackburn’s paper titled, *The function and structure of telomeres* (1991). Blackburn renders a complex subject succinctly and simply enough for most people to understand. The introduction is impressive. Blackburn’s introduction has been there in the background as I have attempted to write a thesis that is both an easy read and engaging. The reader will be the judge.

CHAPTER 1: INTRODUCTION

> *Qualitative researchers have a natural curiosity that leads them to study worlds that interest them and that they otherwise might not have access to. Furthermore, qualitative researchers enjoy playing with words, making order out of seeming disorder and thinking in terms of complex relationships. For them qualitative research is a challenge that brings the whole self into the process.*
>
> *(Corbin & Strauss, 2008, p. 13)*

This introductory chapter provides a blueprint for the thesis. The significance and the rationale of the study are presented, followed by the aim of the study and the context in which the study was undertaken. The researcher then outlines the research design, which Birks and Mills (2011) refer to as the 'blueprint' for a study. The research design includes the methodological 'lens' (Birks & Mills, 2011) through which the researcher conducted the study and the methods used to achieve the desired outcome, including methods for disseminating the study findings. A chapter-by-chapter outline of the thesis provides the reader with an overview of the content of each chapter. The closing sections of the chapter explain the visual representation of information and key terminology used throughout the thesis.

Significance and rationale

The representation of consumers in the history of Western medicine has traditionally been neglected in favour of the control and conquest of diseases, medical practitioners' achievements and the development of institutions (Digby, 1997; Pickstone, 2012). Early recorded instances of consumers in health care were often limited to consumers subjective accounts of illness and treatments, and to case notes recorded in institutional registers (Digby, 1997; Drake, Deegan, & Rapp, 2010). Since the 1970s consumers have increasingly featured in the literature as consenting participants in research studies. This coincides with the evolution of the relationship between consumers and experts, particularly medical practitioners. According to Digby (1997, p. 303), the relationship has evolved from:

> *one of activity by the doctor and passivity by the patient; this was then succeeded by guidance and leadership by the doctor and obedience and admiration by the patient; and the third stage – allegedly reached by the twentieth century – was one of mutual participation and interdependence between practitioner and patient.*

Under the biomedical model of health care that predominated in Western health care systems until the 1970s, the human body and how it was affected by illness were central to treating patients to the exclusion of patients' experience of illness. The introduction of the bio-psychosocial model of health care in the 1970s shifted the emphasis to the patient's psychological and social contexts being viewed in conjunction with their illness. By the 1990s health policy had introduced the concept of consumer/patient/person centred care, which emphasises the provision of health care that respects and is responsive to consumers values, needs and preferences (Committee on Quality of Health Care in America, 2001). With the evolution of the traditional doctor-patient relationship, changes to concepts and models of health care and the rise of the consumer movement, the importance of consumers' perspectives and experiences is recognised and documented in the research literature. Insight into consumers' perspectives and experiences is an important indicator of how health systems are performing and where improvements can be made (Raven, 2013).

When consumers are represented in the literature they are often categorised according to their illness or contextualised within specific health settings (See: Ferri, Muzalupo, & Di Lorenzo, 2015; Lammers & Happell, 2003; Mathur et al., 2013; Tobin, Chen, & Leathley, 2002). Similarly, research into interactions between consumers and health professionals often categorises or contextualises consumers (See: Dell'api, Rennick, & Rosmus, 2007; Faux & Young Seideman, 1996; Howell et al., 2014), focuses on interactions with specific health professionals (Jangland, Larsson, & Gunningberg, 2011; Stenhouse, 2011) or addresses interactions from methodological or conceptual perspectives (See: Cahill et al., 2008; Drew, Chatwin, & Collins, 2001; Sofaer & Firminger, 2005).

Justification

Consumer-centred care requires consumers to share power and responsibility for their health and health care with experts (Mead & Bower, 2000). Supporting consumers to become more involved in their own health and health care requires insight into consumers' perspectives of interactions with experts. Mechanisms such as the National Safety and Quality Health Service Standards (Australian Commission on Safety and Quality in Health Care (ACSQHC), 2011) impose regulatory requirements on health care organisations to engage with consumers and to develop mechanisms for consumers to participate in the planning, service provision, evaluation and improvement of health care services. Such regulatory frameworks have led to focused strategies such as the "Consumer and Community Engagement Framework" (Health Consumers Queensland, 2012).

Gaining insight into processes of interaction between consumers and experts across health care settings and health conditions enables improved efficiencies in the delivery and quality of health care services and has the potential to improve consumer health outcomes and consumers' experiences of health care. Findings from this study will inform individuals, consumer groups, experts, health service providers and governments about strategies to support the continual improvement of interactions between consumers and experts. The resultant grounded theory, from this study, has the potential to inform health care in a variety of settings.

How does this study make an original contribution to the literature?

This study provides insights into processes of interaction between consumers and experts that are not bound by specific health settings or health conditions. This study makes an original contribution to the literature, as it addresses the gap in the literature about this topic.

Aim

The aim of this study is to construct a grounded theory to explain processes of interaction between consumers and experts.

Context

This study was conducted in the Australian regional city of Cairns in far north Queensland. The Cairns region covers a total area of 4,288.4 km2 and, as at 30 June 2013, had an estimated resident population of 171,299 (Queensland Government Statistician's Office, 2014). Cairns has two hospitals; one public and one private. The public hospital provides specialist, community and emergency services for people living in the Cairns region and it is also a major referral centre for people living within Tropical North Queensland (Queensland Government, 2014). The private hospital provides specialist services across the same area. There are approximately two hundred general practitioners working in private practices, Indigenous health services and not-for-profit organisations in the Cairns region (FNQDocs).

Research design

Methodology

The aim of the study and the area of inquiry guided the researcher’s choice of methodology and methods. The aim of the study is to construct a theory that explains the area of inquiry. The researcher used a grounded theory approach as it provides a comprehensive and integrated approach to conducting research, which aims to generate conceptual theory grounded in the data. A grounded theory research design was selected, as it is an appropriate way to examine an area of study in which there is little prior knowledge. Grounded theory studies do not use a priori theories nor are they based on a specific research question/s. Grounded theory studies are based on an area of inquiry, which is broad enough to allow the flexible application of essential grounded theory methods to guide the collection, generation and analysis of data to construct a theory (Charmaz, 2014).

The area of inquiry of the study is the process of interaction between consumers and experts. The researcher selected an evolved grounded theory approach as this ‘version’ of grounded theory is underpinned by symbolic interactionism (Corbin & Strauss, 2008). A symbolic interactionist perspective of social life emphasises, "that society is a process of individuals in interaction" (Charon, 2007, p. 189). Conducting this study using an evolved grounded theory approach provides congruence between the aim of the study and the area of inquiry.

Methods

The following essential grounded theory research methods were used in this study: concurrent data generation or collection and data analysis, initial and intermediate coding of data, constant comparative analysis of data, theoretical sampling of participants, theoretical integration of data, selecting a core category and memo writing (Birks & Mills, 2011).

Sampling and recruitment

The researcher used purposive and theoretical sampling techniques in this study. This resulted in a total of 32 participants, comprising 23 health consumers and nine health experts.

Data collection

The terms ‘collection’ and ‘generation’ of data are used throughout this thesis to differentiate respectively between data that is collected *from* participants and data that is generated *with* participants (Birks & Mills, 2011). Demographic data was collected from participants via a demographic information questionnaire. Data generation methods included: semi-structured interviews, consumer participants’ diary entries, consumers’ digital stories and non-participant observation. The latter was conducted in a hospital setting, general practice and in the community.

Data analysis

The researcher used the grounded theory data analysis methods of concurrent data generation and analysis, initial and intermediate coding, constant comparative analysis and theoretical integration. The researcher used Microsoft® Word, Microsoft® Excel and manual data analysis techniques following a system of data analysis developed by Hahn (2008).

Ethics

This study received ethics approval from the Far North Queensland Human Research Ethics and the James Cook University Human Ethics Research Committee.

Data storage

Study data were managed in accordance with James Cook University policy.

Dissemination of findings

Publications

This research study has resulted in two publications to date. The publication titled: *Terminology used to describe health care teams: An integrative review of the literature* (Chamberlain-Salaun, Mills, & Usher, 2013b) is included in Chapter 2: Background. The publication titled: *Linking symbolic interactionism and grounded theory methods in a research design: From Corbin and Strauss' assumptions to action* (Chamberlain-Salaun, Mills, & Usher, 2013a) is included in Chapter 3: Methodology. Future publications will include: *Outsiders in the experts' world: A grounded theory study*, which will be based on study findings presented in Chapter 5: Findings and *Digital storytelling as a data collection method in a grounded theory study*.

Conference presentations

The researcher attended and presented three papers at the International Congress of Qualitative Inquiry in May 2014. The Congress was held at the University of Illinois in Champaign-Urbana, Illinois, USA. Presentations included: 1) *Linking symbolic interactionism and grounded theory methods in a research design: From Corbin and Strauss' assumptions to action*; 2) *The use of digital storytelling in a grounded theory study;* and 3) *Findings from a grounded theory study*.

Public lecture

Findings from the study will also be disseminated via a public lecture to be held at James Cook University. All study participants will be invited to attend.

Outline of thesis

The **Prologue** included at the beginning of this thesis provides an overview of the researcher's personal history and how this influenced both her decision to undertake a PhD study and her choice of the substantive area of inquiry. Although the prologue has been revised and edited, much of the content was written prior to officially commencing this PhD study. Writing the content of the prologue prior to and during the very early stages of the PhD study enabled the researcher to reflect on her world-view, which in turn influenced the study design.

Chapter 2: Background opens with a discussion about the debate of the literature review in grounded theory studies. Although a traditional literature review is not a feature of grounded theory studies, researchers do not embark on a study without some prior understanding, knowledge and/or experience relating to the substantive area of inquiry. In Chapter 2 the researcher discusses the range of terminology used to describe both health care teams and people who access health services and contextualises the use of the term 'consumer' in this thesis. This chapter includes the publication *Terminology used to describe health care teams: An integrative review of the literature* (Chamberlain-Salaun et al., 2013b).

Chapter 3: Methodology provides details of the research design, including justification for using an evolved grounded theory approach. The reader is also provided with a description of the essential grounded theory methods used in this study. The chapter concludes with the publication *Linking symbolic interactionism and grounded theory methods in a research design: From Corbin and Strauss' assumptions to action* (Chamberlain-Salaun et al., 2013a).

How the essential grounded theory methods were used in this research study is featured in **Chapter 4: Method**. The chapter also includes details of the five data collection and generation strategies used within the grounded theory research process.

Chapter 5: Findings presents the grounded theory *Outsiders in the experts' world.* The grounded theory consists of five categories: Unexpected entrance, Learning a new role, Establishing a presence, Confronting the dichotomy of 'us and them' and Tailored care. Four of the five categories also comprise sub-categories. Chapter 5 also includes an electronic link to a digital story that uses images and sound to re-present the grounded theory. The researcher constructed the story from participant's own words, with the aim of providing a digital representation of the grounded theory. It also serves as an example of a digital story, for readers who are unfamiliar with the medium.

In **Chapter 6: Discussion**, the researcher discusses the study findings within the context of the broader literature, with reference to the extant concepts and or theories of culture shock, health literacy and bridging the dichotomies of the consumer-expert relationship. These concepts and theories were not imposed during the grounded theory research process; rather they are used to enhance the explanatory power of the grounded theory presented in this thesis.

Chapter 7: Conclusion provides a conclusion to the thesis. The chapter includes researcher recommendations for policy, research, education and practice and evaluates the quality of the grounded theory process and the grounded theory product of this study.

The **Epilogue**, which 'book-ends' the thesis is the researcher's reflections on the research process and the research study. Including a prologue and an epilogue provides the reader with some insight into the researcher as a person and provides subjective accounts of her personal history, reflections and experiences. Both the prologue and the epilogue are written in the first person.

Visual representation of information

The researcher has used a range of visual formats to display information throughout the thesis. To enable consistent and easy to follow sequencing, the researcher has elected to follow Dunleavy's (2014) suggestion to label all tables, models, flowcharts, example boxes etcetera, as Figures. Traditionally in academic writing, 'tables' contain numbers and text and 'figures' contain graph elements such as lines or bars. In the digital era, information is represented in a broader range of formats limited only by the imagination. As Dunleavy (2014) highlights, the separation of “exhibits” into categories such as tables and figures “is artificial and out of date” (Section 4: Para. 1) and unnecessarily complicates readers’ search for information and back referencing in written work. A list of Figures included in this thesis can be found on page xi.

Definitions

Two key terms, which are central to the grounded theory presented in this thesis are: consumer and expert. The term ‘consumer’ is used to refer to people, including carers, who access health services. In instances where the literature or participants use alternate terms such as patient or client, the researcher has remained faithful to the original text or spoken word. Although the literature suggests that the term consumer has market-based economic inferences, as discussed in Chapter 2, the researcher’s choice of the term consumer was influenced by the use of this term in Australian government policy documents and a personal belief that the term patient suggests passivity.

The term ‘expert’ is used to signify all health professionals, unless the context of the text refers to, or requires specific health professionals to be identified. The use of the term ‘expert’ links consumer study participants overall acknowledgement of, and reliance on, the expertise of health professionals and the title of the grounded theory, *Outsiders in the experts’ world*, which forms the basis of Chapter 5: Findings. A glossary of all key terms used in this thesis is provided on page xii.

Chapter summary

This chapter provided the reader with the significance, justification and aim of the study. The design of the study is explained and includes the methodological perspective of the study, methods used to conduct the study and mechanisms for disseminating study findings. A chapter-by-chapter overview of the thesis provides the reader with an outline of the contents of each chapter. The use of and justification for the terms consumer and expert conclude the chapter.

The following chapter provides a background to the study. In grounded theory research the place of the literature review has been heavily debated. The following chapter opens with an overview of the debate concerning this issue. Following the pragmatic approach of Strauss and Corbin, the literature concerned with the substantive area of inquiry is then explored. The chapter includes an integrative review of the literature examining terminology used to describe healthcare teams and also explores terminology used to describe healthcare consumers.

PUBLICATION CONTRIBUTION

The following chapter contains a published manuscript. All authors agree to be accountable for all aspects of the published work.

Chamberlain Salaun, J., Mills, J., & Usher, K. (2013). Terminology used to describe health care teams: an integrative review of the literature. *Journal of Multidisciplinary Healthcare, 6*, 10. doi: ttp://dx.doi.org/10.2147/JMDH.S40676

The authors agree that they contributed as follows:

Jennifer Chamberlain-Salaun

- Conception and design of the work
- Analysis and interpretation of data
- Drafting the article
- Final approval of the published version

Jane Mills and Kim Usher

- Analysis and interpretation of data
- Revising the work for important intellectual content
- Final approval of the published version

Jennifer Chamberlain-Salaun 10th March 2015	Jane Mills 10th March, 2015	Kim Usher 10th March, 2015

CHAPTER 2: BACKGROUND

> *The broad field of human wisdom has been cut into a multitude of little professional rabbit warrens. In each of these a specialist burrows deep, scratching a shower of terminology, head down in an unlovely attitude which places an interlocutor at a grotesque conversational disadvantage.*
>
> *(Leacock, 1916, pp. 44-45)*

> *The patient asks HealthTap, "What caused my arm pain during my recent heart attack?" And the cardiac surgeon replies to the patient, "The pericardium is immervated by C3, 4 5 (Phrenic nerve). There may be some neuronal connections to the intercostobrachial nerves".*
>
> *(Thomas, 2013, pp., para. 2)*

There has previously been much debate among the grounded theory community about the place of the literature review in grounded theory studies. This chapter opens with an overview of the debate and the current thinking and reality of the literature in grounded theory studies. The following section of the chapter is dedicated to the topic of the language of health care. Silverman (2011b) suggests that researchers need to broaden their conceptions of qualitative research beyond "issues of subjective 'meaning' and towards issues [including…] language" (p. 4). With this in mind, the researcher conducted a literature review of terminology used to describe health care teams and the resultant publication is included in the chapter. The publication is followed by a discussion around terminology used to describe people who access health services and the place of consumers in health care. This chapter provides a background to the study's area of inquiry.

The place of the literature review in grounded theory studies

Research studies traditionally include a literature review. In research studies, which aim to either prove or disprove a theory or hypothesis, answer specific research questions or provide a descriptive analysis of phenomena, it is common practice to conduct a literature review prior to or in the early stages of the study. Conducting a literature review in these instances enables researchers to identify current knowledge and the ‘state of play’ in relation to their research study topic. A formal literature review is not common practice in grounded theory research because studies are not based on a priori assumptions, hypotheses or specific research questions. The place of a literature review in grounded theory studies has not been, however, without debate.

The debate about the place of a literature review in grounded theory studies has been extensively discussed and reviewed in the literature (Birks & Mills, 2011; Charmaz, 2014; Urquhart, 2013). The debate has largely been fuelled by misinterpretations of Glaser and Strauss’ (1967) use of the term *tabula rasa* (blank slate). Charmaz (2014) suggests that some authors interpreted the use of the term to mean Glaser and Strauss were advocating that researchers reject any prior knowledge, prior experience and any preconceptions in relation to an area of inquiry. The debate has been fuelled further by suggestions that extensively reviewing the literature in the early stages of a grounded theory study may influence the researcher to preconceptualise and/or to force and overlay extant theories on the collection and analysis of data (Glaser, 1978, 2012; Glaser & Holton, 2007). Countering previous claims about the place of a literature review in grounded theory studies, Thornberg (2012) proposes an ‘informed grounded theory’ approach in which researchers sensitively, creatively and flexibly take advantage of their knowledge of pre-existing theories and research findings in the substantive area of inquiry of their study.

Despite previous debate about the place of the literature review in grounded theory studies, it is now generally accepted that a formal literature review should not be conducted in the substantive area of inquiry. It is also acknowledged that researchers do not approach a study devoid of prior knowledge, experience or preconceptions (Birks & Mills, 2011; Charmaz, 2014; Thornberg & Charmaz, 2011; Urquhart, 2013). Critically reflecting on these factors enables researchers to remain open to what is going on in the data and the developing theory in their study (Birks & Mills, 2011; Charmaz, 2014; Glaser, 2012). Corbin and Strauss (2008) also suggest that when conducting grounded theory studies, researchers ask themselves if codes and categories that they attribute to data in their own studies are “truly derived from data or [are researchers] imposing these concepts on the data because [they are] so familiar with them?" (p. 37). In instances where research reporting requirements follow a "standard – rigid – format" (Charmaz, 2014, p. 308), which includes a literature review, researchers are cautioned to use the literature without allowing it to "stifle […] creativity or strangle […] theory" (Charmaz, 2014, p. 308).

In this study, the researcher engaged with the literature to establish terminology usage about descriptors used to describe health care teams and terminology used to describe people who access health services. The researcher's aim was to gain understanding of terminology being used, which would guide decisions about terminology usage in this study. Engagement with the literature resulted in the publication *Terminology used to describe health care teams: An integrative review of the literature* (Chamberlain-Salaun et al., 2013b), which features below in this chapter. Additionally, engaging with the literature raised the researcher's theoretical sensitivity to the issue of terminology usage in health and the importance of language in interactions between all health stakeholders.

The language of health care

Language is defined as "any set or system of such symbols as used in a more or less uniform fashion by a number of people, who are thus enabled to communicate intelligibly with one another" (Macquarie University, 1995). For language to be used in a uniform fashion for the purposes of meaningful communication it must, however, have intersubjective meaning for all individuals involved (Mead, 1934). The language of health care is developed by policy makers and researchers and propagated by educational institutions, academics and those working within the health service industry. Within the health care sector, terminology is not necessarily used uniformly nor does it necessarily have intersubjective meaning for those using it, which raises issues for meaningful and effective communications between stakeholders, including consumers. Partida (2012) suggests, "health communications should be seen as similar to foreign language exchanges that require proactive attention to the use of language" (p. 22). However, prior to terminology usage, proactive attention to developing and establishing terminology that has shared meanings for all stakeholders is required. The literature demonstrates that those developing and using the language of health care do not share intersubjective meanings, as the following publication highlights.

Publication 1

Chamberlain Salaun, J., Mills, J., & Usher, K. (2013). Terminology used to describe health care teams: an integrative review of the literature. *Journal of Multidisciplinary Healthcare, 6*, 10. doi: ttp://dx.doi.org/10.2147/JMDH.S40676

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REVIEW

Terminology used to describe health care teams: an integrative review of the literature

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Purpose: Health systems around the world are struggling to meet the needs of aging populations and increasing numbers of clients with complex health conditions. Faced with multiple health system challenges, governments are advocating for team-based approaches to health care. Key descriptors used to describe health care teams include "interprofessional," "multiprofessional," "interdisciplinary," and "multidisciplinary." Until now there has been no review of the use of terminology relating to health care teams. The purpose of this integrative review is to provide a descriptive analysis of terminology used to describe health care teams.

Methods: An integrative review of the literature was conducted because it allows for the inclusion of literature related to studies using diverse methodologies. The authors searched the literature using the terms interprofessional, multiprofessional, interdisciplinary, and multidisciplinary combined with "health teams" and "health care teams." Refining strategies included a requirement that journal articles define the term used to describe health care teams and include a list of health care team members. The literature selection process resulted in the inclusion of 17 journal articles in this review.

Results: Multidisciplinary is more frequently used than other terminology to describe health care teams. The findings in this review relate to frequency of terminology usage, justifications for use of specific terminology, commonalities and patterns related to country of origin of research studies and health care areas, ways in which terminology is used, structure of team membership, and perspectives of definitions used.

Conclusion: Stakeholders across the health care continuum share responsibility for developing and consistently using terminology that is both common and meaningful. Notwithstanding some congruence in terminology usage, this review highlights inconsistencies in the literature and suggests that broad debate among policy makers, clinicians, educators, researchers, and consumers is still required to reach useful consensus.

Keywords: descriptors, interprofessional, multiprofessional, interdisciplinary, multidisciplinary

Introduction

Health systems, particularly those in industrialized countries, are struggling to meet both the needs of aging populations and growing numbers of clients with multiple and complex health issues.[1] Additionally, health systems face cost constraints, workforce shortage pressures, and increasing complexity of required health care knowledge.[2–4] Historically, interactions between health professionals have been authoritarian and dominated by doctors.[5] Faced with multiple health system challenges, governments are advocating for more team-based approaches to health care,[3,6,7] to increase the number and balance of complementary contributions to client-focused care.[8]

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Journal of Multidisciplinary Healthcare 2013:6 65–74

A recent report on team-based health care emphasizes the potential of teams to improve the value of health care.[9] Health professionals working in teams to deliver health care is neither a new concept nor a new practice. The concept of team care was mooted and documented as early as 1920, in a report to the UK Minister of Health[10] recommending that "General Practitioners; Visiting Consultants and Specialists; Officers engaged in Communal Services; Visiting Dental Surgeons; [and] Workers in ancillary services" work together in primary health centers. The practical implementation of health care teams can be traced to the development of Engel's 1977 biopsychosocial model of health.[11–13] The model incorporates social, psychological, and behavioral dimensions of illness[13] and seeks to address inadequacies in the traditional biomedical model of care in which disease, and not the client, predominates.[14] Engel[13] asserted that a more holistic model of care could be achieved with a shift in focus from doctor-centric service delivery to health care services delivered by teams of professionals.

"Health care teams" as an area of research is well documented. A search of the CINAHL® database for English-language text using the terms health care team "OR" health team in the "TX All Text" field returned 2917 articles published since 2000. Descriptors such as "interprofessional," "multiprofessional," "interdisciplinary," and "multidisciplinary" are terms used to describe both members of different professions working together as health care teams and ways in which health care teams collaborate. Inconsistencies in terms used to describe health care teams in either context, including the interchangeable use of terms, are apparent in the literature and are highlighted by numerous researchers.[8,15–19] A search of the literature did not find any reviews that have specifically considered patterns of terminology usage.

While standardized definitions of terms used to describe different health care teams may not be feasible, given the complexity of health care contexts, gaining an understanding of current patterns of usage will contribute to greater consistency in the use of terminology. Gaining an understanding of how and in which context health care team descriptors are being used provides a departure point from which stakeholders can reflect on terminology usage prior to developing interprofessional education programs, conducting research, writing policy, or developing teams. Consistency in the use of terms to describe different health care teams in policy, education, training, clinical practice, and research could improve communication between sectors, enable individual groups to focus on improving the contribution that each make to the client health care journey, and provide greater clarity for consumers.

Until now there has been no review of the use of terminology relating to health care teams. A clearly identified gap in the literature makes the findings of this integrative review significant in developing this substantive area of inquiry. The purpose of this integrative review is to provide a descriptive analysis of terminology used to describe health care teams.

Methods

A search of the CINAHL and Web of Science® (Thomson Reuters Web of Knowledge) databases was conducted using the following criteria: English-language text published between 2000 and 2011. The search terms in the "TX All Text" field in CINAHL and in the "TS (topic)" field in Web of Science were interprofessional "OR" multiprofessional "OR" interdisciplinary "OR" multidisciplinary combined with "AND" health team "OR" health care team. Dissertations and theses were excluded from the search strategy.

Abstracts of all journal articles returned in the search were screened and the articles were retained if the abstract included one or more of the terms interprofessional, multiprofessional, interdisciplinary or multidisciplinary and the term "health team" or "health care team." The full text of retained articles was then screened and the articles were retained if they included a definition of interprofessional, multiprofessional, interdisciplinary, or multidisciplinary; if they identified health care team members; and if they related to health care teams in health practice settings. This resulted in 17 journal articles being included in this integrative review (Table 1).

An integrative literature review is the broadest type of research review method. It enables a fuller understanding of phenomena, as it allows for the inclusion of literature related to studies using diverse methodologies.[20,21] As the phenomenon of this review is the use of terminology to describe health care teams, included journal articles were not methodologically critiqued or assessed using a hierarchy of evidence-for-practice, although assessment is often performed in literature reviews.

During the literature search for this integrative review, the authors found a substantial number of journal articles relating to health care teams in the context of education. The authors observed that the term interprofessional is consistently used in relation to the joint education of health professionals from various health professions and disciplines. A separate review of the literature would need to be conducted to provide

Table 1 Articles meeting selection criteria for inclusion

Reference	Terminology used	Definition	Country	Setting	Health area	Team members
Atwal and Caldwell[24]	Multidisciplinary	Team members "having different professional backgrounds but who make complementary contributions to patient care"	UK	Acute care – hospital wards	Elder care Orthopedics Acute medicine	Doctor, nurse, occupational therapist, physiotherapist, and social worker
Black[11]	Interdisciplinary	Team members "[interact] to produce a final outcome on behalf of patients"	USA	Hospital – private, not-for-profit	Elder care	Medicine, nursing, and social work
Chan et al[27]	Multidisciplinary	"Team care coordinated by a leader who takes responsibility for overall patient care. Members contribute views and recommendations according to their particular expertise, which may be integrated by the leader"	Australia	General practice and community health care	Chronic disease	General practitioners and allied health providers including podiatrists, optometrists, diabetes educators, dietitians, cardiac rehabilitation workers, exercise physiologists, and psychologists
Cioffi et al[28]	Multidisciplinary	Use the definition provided by Schofield and Amodeo[19]: "a number of individuals from various disciplines [who] are involved in a project but work independently"	Australia	Community health care	Chronic disease	Community nurses, occupational therapist, physiotherapist, and social workers
Delva et al[31]	Interdisciplinary	"Groups of professionals who work collaboratively to develop processes and plans for patients"	Canada	University primary care teaching practice	Primary care	Teaching teams consisting of physicians, nurses, resident physicians, receptionist, secretaries, nutritionists, social workers, and administrative staff
Gibbon et al[25]	Interprofessional	"'Processes' of intervention"	UK	Hospital – stroke rehabilitation units	Stroke patients	Nurses, doctors, physiotherapists, occupational therapists, speech and language therapists, social workers, and clinical psychologist
	Multiprofessional	"The 'structural' components of a team"	UK	Hospital – stroke rehabilitation units	Stroke patients	Nurses, doctors, physiotherapists, occupational therapists, speech and language therapists, social workers, and clinical psychologist
Goldsmith et al[29]	Interdisciplinary	"Collaboration among health care providers with specialized knowledge from multiple disciplines"	USA	Veterans Affairs hospital	Geriatric and palliative care	Social worker, chaplain, psychologist, nurse, and doctors
Haggerty et al[33]	Multidisciplinary	"Practitioners from various health disciplines collaborate in providing ongoing health care"	Canada	Community	Primary health care	Study based on Canadian primary health care experts: family physicians, nurses, academics, and decision makers
Kim et al[60]	Multidisciplinary	Specific to primary health care the authors define multidisciplinary as "PHC [primary health care] delivered by health professionals from multiple disciplines, including nurses, physicians, dentists, and public health doctors"	Korea	Nursing faculty and primary health care	Primary health care	Nurse, physician, social workers, and dentists
Kuder et al[30]	Interdisciplinary	"A team integrates its various disciplinary perspectives and maintains a network of cooperation and communication"	USA	Rural geriatric health care	Gerontology	Physician, nurse practitioner or physician assistant, pharmacist, and social worker

(*Continued*)

Table 1 (*Continued*)

Reference	Terminology used	Definition	Country	Setting	Health area	Team members
Kvarnström[26]	Interprofessional	"'Inter' relates to the dimension of collaboration [...] 'profession' [...] differentiates from the term 'discipline' in the sense that disciplines may be regarded as academic disciplines as well as sub-specialities within professions"	Sweden	Swedish local health care settings	Primary care, psychiatric care, geriatric care, rehabilitation	Occupational therapist, registered nurse, physiotherapist, medical social worker, administrative assistant, physician, practical nurse, psychologist, and speech therapist
Mills et al[35]	Interprofessional	"Teams work jointly to provide health care, where each member of the team contributes within the context of his or her profession"	Australia	Remote or isolated	Primary health care	Medical officers, specialist nurses, indigenous health workers, local indigenous health service managers, distant health service managers, and allied health professionals
Molleman et al[36]	Multidisciplinary	"Care providers with a range of occupational backgrounds collectively discussing a patient leading to collective decision-making and action"	Holland	N/A – survey distributed to medical specialists (nonspecific to setting)	Oncology and geriatrics	Geriatric team: head of geriatric department, clinical geriatrician, geriatrician internist, resident internal medicine specialist, psychiatrist, neurologist, social worker, specialized nurses, and psychologist Oncology team: intern oncologist, hematologist, specialized nurse, internal medicine resident, radiotherapist, social worker, dietitian, physiotherapist, mental care assistant, clinical chemist, pharmacist, and microbiologist
Molleman et al[44]	Multidisciplinary	Use the terminology in the context of medical teamwork: "work arrangement in which physicians from different medical specialities regularly meet to share, weigh and synthesize information concerning individual patients from a specific patient group, and where they, at least to some extent, collectively make decisions about diagnoses and treatment"	Holland	Hospital	Medical specialties	Physicians from different medical specialties
Shaw[32]	Interprofessional	Use the definition provided by D'Amour and Oandasan[33]: "The development of cohesive practice between professionals from different disciplines […] it involves continuous interaction and knowledge sharing between professionals [...] all while seeking to optimize the patient's participation"	Canada	Family health center in an urban teaching hospital	Primary care	Nurse, family physician, family medicine residents, dietitian, and pharmacist

Solheim et al[23]	Multidisciplinary	"Members maintain discipline-specific roles"	USA	Community	Primary health care	Nurse (nurse participants identified physicians and social workers as collaborators in team-based primary health care)
Spencer and Cooper[45]	Multidisciplinary	"Interdependency with other professionals and being able to combine perceptions and skills to synthesise a more complex and comprehensive plan of care"	UK	Hospital	Type 1 diabetes	General pediatric consultant, specialist nurse, specialist dietitian, and general psychologist

Notes: Primary care draws from the biomedical model. It is a person's first point of entry into the health system. Primary health care draws from the social model of health. It considers that people's basic needs must first be met in order for health gain to occur.[59]

Abbreviation: N/A, not applicable.

evidence for this observation. The authors acknowledge that the terminology used in health care education may affect the terminology used in practice. However, given the extent of literature relating to health care teams in educational contexts, journal articles relating to health care teams in the context of education were excluded from this literature review.

Included articles were reviewed to ascertain how terminology used to describe health care teams is defined in the literature. Comparative analysis of journal articles resulted in findings that relate to frequency of terminology usage, justifications for use of specific terminology, commonalities and patterns related to country of origin of research studies and health care areas, ways in which terminology is used, structure of team membership, and perspectives of definitions used. Table 1 presents data extracted from the included articles. The Discussion section of this article contextualizes findings in this review within the broader literature.

Figure 1 demonstrates the literature selection process. The flowchart is adapted from an original flowchart developed for systematic reviews.[22]

Findings

This integrative review of the literature found that the term multidisciplinary is used more frequently than other terms to describe health care teams. Of the 17 journal

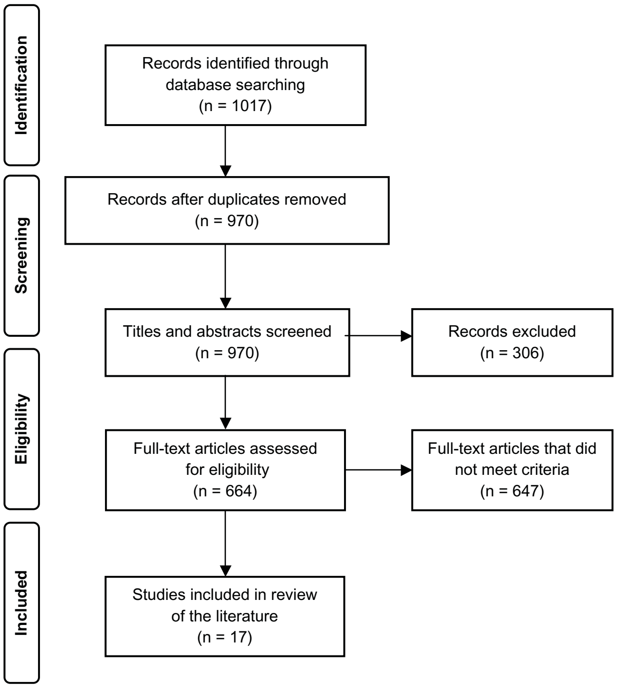


Figure 1 Flowchart of literature selection process.

Note: Adapted with permission from Moher D, Liberati A, Tetzlaff J, Altman DG; PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA Statement. *PLoS Med.* 2009;6(7):e1000097.[22]

articles included in this review, nine use multidisciplinary, four use interdisciplinary, and three use interprofessional; the remaining article uses both multiprofessional and interprofessional (Table 1).

While all studies define the term used, only four studies justify their choice of terminology. Solheim et al[23] acknowledge distinctions between the terms multidisciplinary and interdisciplinary and base their use of multidisciplinary "on the value of having more than one discipline on a team." Atwal and Caldwell's[24] use of the term multidisciplinary in their study is justified as follows: "the experience of working together in a multidisciplinary team was one that was common to all nurses within the study area, whereas working interprofessionally was less well understood."

Gibbon et al[25] chose to use the term multiprofessional in reference to the structural components of a team and the term interprofessional in reference to processes of intervention. Kvarnström's[26] study into health professionals' perceived difficulties in teamwork uses the term interprofessional, stating: "the prefix 'inter' relates to the dimension of 'collaboration' [… and] the term 'profession' thus different[iates] from the term 'discipline' in the sense that disciplines may be regarded as academic disciplines or sub-specialties within professions."

The term multidisciplinary is used in the two Australian studies relating to chronic disease.[27,28] Of the four studies conducted in the United States, three relate to geriatric care and all three use the term interdisciplinary.[11,29,30] There is no consistency of terminology usage in the three Canadian studies included in this review: Delva et al[31] use the term interdisciplinary, Shaw[32] uses interprofessional, and Haggerty et al[33] use multidisciplinary. Although, the article by Haggerty et al[33] does not define the members of a multidisciplinary team per se, the study includes family physicians, nurses, academics, and decision makers, and it asks participants to define an operational definition for "multidisciplinary team." This question resulted in more than 80% of Haggerty et al's[33] study participants agreeing to the following definition for multidisciplinary teams: "practitioners from various health disciplines [who] collaborate in providing ongoing health care."[33]

Findings indicate that terminology used to describe health care teams refers in some instances to the structural component of a team; for example, Gibbon et al[25] use the term multiprofessional to describe teams in their study. Other findings indicate that terminology reflects the way in which teams collaborate. Delva et al[31] use the term interdisciplinary to define the collaborative ways in which groups of professionals work together to develop processes and plans for patients. Shaw's[32] use of the term interprofessional, as defined by D'Amour and Oandasan,[34] encompasses both dimensions of collaboration and professions working together (refer Table 1). These examples highlight inconsistencies relating to how terminology is used in the literature.

Regardless of the terms used and regardless of whether the terminology describes members of different professions working together in a team or the way in which team members collaborate, all included journal articles refer to the structural composition of health care teams. Teams are composed of members from a range of professional backgrounds and disciplines (Table 1). Doctors and nurses are members of all health care teams featured in the included literature. Generally, teams also include a range of allied health professionals and other specialist health professionals, depending on the health area and setting in which the teams operate.

A number of studies also include laypeople as members of health care teams. Delva et al[31] include receptionists, secretaries, and administrative staff as members of interdisciplinary teams in primary care teaching practices. A study by Mills et al[35] includes indigenous health service managers and district health service managers as members of interprofessional health care teams in remote areas of Queensland, Australia. These positions are held by both health and non-health professionals. Chaplains are included as members of interdisciplinary geriatric and palliative care teams in the study by Goldsmith et al.[29] Medication and medication management are key elements in the treatment of most health conditions; pharmacists, however, are included as health care team members in only three[30,32,36] of the 17 articles included in this review.

Almost all of the journal articles include definitions of health care teams that reflect a provider-centric perspective. Of the 17 articles, only one[32] includes a definition that refers to the participation of patients. Other definitions that refer to patients tend to reflect a traditional model of care in which health professionals are active participants and patients are passive recipients of care. For example, in the article by Atwal and Caldwell,[24] "team members […] make contributions to patient care"; in the article by Chan et al,[27] "a leader […] takes responsibility for overall patient care"; and in the article by Molleman et al,[36] "care providers collectively [discuss] a patient leading to […] decision-making and action." Conversely, D'Amour and Oandasan's[34] definition of interprofessional, as adopted by Shaw,[32] suggests that patients are encouraged to play an active role in teams, as teams "[seek] to optimize the patient's participation."

Discussion

Thylefors et al[37] assert that, in the broader literature, interprofessional, multiprofessional, interdisciplinary, and multidisciplinary appear to be the terms most frequently used to describe health care teams. Although standardized definitions for each term have not been broadly adopted, the Interprofessional Education Collaborative Expert Panel,[38] in a 2011 report on collaborative practice, recommends terminology and operational definitions around interprofessional team work. Additionally, conceptual frameworks that situate teams on a collaborative continuum also provide guidance around terminology usage.[39,40] Nonetheless, the broader literature shows some generally accepted features of commonly used terminology. The prefix "multi" means "more than one; many."[41] Terminology prefixed by "multi" generally refers to team members from different disciplines working parallel to one another to treat clients. Members share information but do not necessarily share common understandings, and the group does not generally follow formal processes.[17,26,42,43]

The prefix "inter" means "between; among […] mutually; reciprocally."[41] The literature suggests that interprofessional and interdisciplinary health care teams tend to have more formal structures, such as shared decision-making and conflict resolution processes. Members work interdependently to pool their knowledge in order to achieve a common goal that results in more than the sum of its parts.[12,15,17,42,43] The notions of interdependence and shared decision making feature in numerous definitions; however, in each instance the authors use the term multidisciplinary (refer Table 1[36,44,45]). These discrepancies support extant literature that highlights inconsistencies in terminology usage and interpretations.[8,15–19,46,47]

The terms interprofessional, multiprofessional, interdisciplinary, and multidisciplinary are terms frequently used to describe health care teams. However, these terms are not always defined. A particular case in point is an article by Maslin-Prothero.[48] Multidisciplinary teams are referred to 31 times in the article without the author once defining what is meant by the term "multidisciplinary team" or identifying team members. The reader does not know who the members of the team are or how the author defines the term multidisciplinary. Well-read scholars may quickly assume a definition based on prior knowledge, regardless of its fit with the type of team referred to in the text. By authors and editors making an assumption that the reader will know what the term used means, they are neglecting the fact that a broad audience, including students, clinicians, policy makers, and academics, access published research. Providing definitions to key terminology used in both published and gray literature enriches the reader's experience.

Analysis of literature included in this review within a broader literature context highlights factors that may influence terminology usage. Of the three Australian studies included in this review, two relate to chronic disease, and in both instances the articles use the term multidisciplinary.[27,28] In contrast, US studies in the areas of geriatric, palliative, and elder care feature the term interdisciplinary.[11,29,30]

Use of the term multidisciplinary in the context of the Australian studies included in this review[27,28] reflects Australian policy decisions. For example, multidisciplinary care and multidisciplinary teams are features of most chronic disease strategies in Australia.[49–53] However, in these strategies reference to multidisciplinary care and multidisciplinary teams is generally only in relation to the structural dimension of professional representation and, in the case of the strategy in New South Wales,[51] to the setting in which teams work. The strategy in Queensland[52] is the only Australian chronic disease strategy to provide a specific definition of multidisciplinary teams.

The Australian Capital Territory chronic disease strategy[54] refers to interprofessional teams. The key feature that differentiates the interprofessional teams referred to in this particular strategy from the multidisciplinary teams referred to in the other State strategies and in the Australian national strategy is the inclusion of the consumer "as a key member of the care team."

The use of the term interdisciplinary in US studies relating to geriatric, palliative, and elder care reflects training and care models used in these specialty health areas and highlights linkages between training and practice.[11,29,30] The importance of providing an interdisciplinary training environment to promote interdisciplinary care models is best evidenced in the area of geriatrics. In 1997 the John A Hartford Foundation funded the development of eight national Geriatric Interdisciplinary Team Training programs in the United States, and this led to approximately 1800 students and 150 practicing health professionals being trained in this area.[16,55]

Approaches to both geriatric and palliative care are grounded in an interdisciplinary/biopsychosocial care model.[29,56] This model promotes holistic, client-focused care delivered by interdisciplinary teams, and it is an integral component of the philosophy of care used in these specialty areas.[56,57]

So just how important is the labeling of health care teams? McCallin[8] contends, "it is possible that the labels assigned to people working together […] are relatively unimportant," particularly when terminology does not reflect the way in which team members interact and deliver care.

However, as Ovretveit[58] cautions, current issues relating to terminology usage arise when designing and improving teams, as "people use the same word to mean something different." Holmes et al[16] consider that "efforts to understand teams fully are hampered due to the diversity of terms in which they are described and conceptualized […] definitional clarity […] [is therefore a] perquisite [sic] to further research on teams." Adopting an overarching term such as "team-based care," as defined by Mitchell et al,[9] is also worth serious consideration. An overarching term that encompasses the principles of team care may well alleviate the need to label specific teams, thereby avoiding inconsistencies in terminological usage.

Consideration of these comments and the findings of this literature review suggest that either the development of a common understanding of current terminology or the adoption of an overarching term to describe health teams would be valuable and would support consistency in the use of terminology in policy, education, training, clinical practice, and research.

Limitations of the review

The articles included in this review were published between 2000 and 2011. A search strategy using a broader time frame may provide evidence of the influence of historical socialization patterns in terminology usage, as McCallin[8] suggests. Because of the large number of articles sourced and the pace of health care changes, the authors elected to limit the literature search to this time frame. This review also included refining search strategies, which required journal articles to include a definition of terminology used and a list of health care team members. A quantitative study of terminology usage that excludes refining search strategies may provide a broader picture of terminology usage and significant evidence of inconsistencies in terminology usage referred to in the broader literature. Additionally, the use and definition of specific terms may differ more extensively between countries and health systems than those referred to in this review.

Conclusion

As population health care needs change, the trend towards teams of health professionals from various disciplines working together to deliver coordinated client care is undeniable. This review demonstrates that a range of terms – interprofessional, multiprofessional, interdisciplinary, and multidisciplinary – are used to describe health care teams. Multidisciplinary is most frequently used to describe health care teams. Patterns of use of the term interdisciplinary are clearly identified in the US geriatric care literature, while the use of multidisciplinary in the two Australian chronic disease studies is reflective of Australian state and national strategies.

It is now more than a decade since Ovretveit[58] concluded that research, discussion, and decision making around "which type of team is best for a particular purpose and setting" requires stakeholders to be able to describe a team. The growing emphasis on interprofessional education and learning within health care and the development of recommended operational definitions and conceptual collaborative frameworks to guide terminology usage, may result in shared definitions that are used in both education and practice. However, the terminology used in national policies and strategies influences the terminology used in funding applications, and the researchers who submit these applications are employed in the tertiary institutions educating the future health workforce.

Stakeholders across the entire health care continuum share responsibility for developing and consistently using terminology that is both common and meaningful. Notwithstanding some congruence in terminology usage, this review highlights inconsistencies in the literature and suggests that broad debate among policy makers, clinicians, educators, researchers, and consumers is still required to reach useful consensus.

Disclosure

The authors report no conflicts of interest in this work.

References

1. Australian Institute of Health and Welfare. *Australia's Health 2008*. Canberra: Australian Institute of Health and Welfare; 2008.
2. Lemieux-Charles L, McGuire W. What do we know about health care team effectiveness? A review of the literature. *Med Care Res Rev*. 2006;63(3):263–300.
3. National Health and Hospitals Reform Commission. *A Healthier Future for All Australians: Final Report June 2009*. Canberra: Australian Government Department of Health and Ageing; 2009.
4. Sierchio GP. A multidisciplinary approach for improving outcomes. *J Infus Nurs*. 2003;26(1):34–43.
5. Fagin CM. Collaboration between nurses and physicians: no longer a choice. *Acad Med*. 1992;67(5):295–303.
6. Detsky AS, Naylor CD. Canada's health care system: reform delayed. *N Engl J Med*. 2003;349(8):804–810.
7. Xyrichis A, Lowton K. What fosters or prevents interprofessional teamworking in primary and community care? A literature review. *Int J Nurs Stud*. 2008;45(1):140–153.
8. McCallin A. Interdisciplinary practice – a matter of teamwork: an integrated literature review. *J Clin Nurs*. 2001;10(4):419–428.

9. Mitchell P, Wynia M, Golden R, et al. *Core Principles and Values of Effective Team-Based Health Care*. Washington, DC: Institute of Medicine; 2012.
10. Addison C. Future provision of medical services: report of the Medical Consultative Council for England. *Br Med J*. 1920;1(3100): 739–743.
11. Black K. Advance directive communications practices: social worker's contributions to the interdisciplinary health care team. *Soc Work Health Care*. 2005;40(3):39–55.
12. Connor SR, Egan KA, Kwilosz DM, Larson DG, Reese DJ. Interdisciplinary approaches to assisting with end-of-life care and decision making. *Am Behav Sci*. 2002;46(3):340–356.
13. Engel GL. The need for a new medical model: a challenge for biomedicine. *J Interprof Care*. 1989;4(1):37–53.
14. Chamberlain-Salaun J, Mills J, Davis N. The general practice team and allied health professionals. In: Caltabiano ML, Ricciardelli L, editors. *Applied Topics in Health Psychology*. Oxford, UK: Wiley-Blackwell; 2012:505–516.
15. D'Amour D, Ferrada-Videla M, San Martin Rodriguez L, Beaulieu MD. The conceptual basis for interprofessional collaboration: core concepts and theoretical frameworks. *J Interprof Care*. 2005;19 Suppl 1: 116–131.
16. Holmes D, Fairchild S, Hyer K, Fulmer T. A definition of geriatric interdisciplinary teams through the application of concept mapping. *Gerontol Geriatr Educ*. 2003;23(1):1–11.
17. McCallin A. Interprofessional practice: learning how to collaborate. *Contemp Nurse*. 2005;20(1):28–37.
18. Mitchell PH. What's in a name? Multidisciplinary, interdisciplinary, and transdisciplinary. *J Prof Nurs*. 2005;21(6):332–334.
19. Schofield RF, Amodeo M. Interdisciplinary teams in health care and human services settings: are they effective? *Health Soc Work*. 1999;24(3):210–219.
20. Schneider Z, Whitehead D, Elliott D. *Nursing and Midwifery Research: Methods and Appraisal for Evidence-Based Practice*, 3rd ed. Sydney, Australia: Mosby Elsevier; 2007.
21. Whittemore R, Knafl K. The integrative review: updated methodology. *J Adv Nurs*. 2005;52(5):546–553.
22. Moher D, Liberati A, Tetzlaff J, Altman DG; PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA Statement. *PLoS Med*. 2009;6(7):e1000097.
23. Solheim K, McElmurry BJ, Kim MJ. Multidisciplinary teamwork in US primary health care. *Soc Sci Med*. 2007;65(3):622–634.
24. Atwal A, Caldwell K. Nurses' perceptions of multidisciplinary team work in acute health-care. *Int J Nurs Pract*. 2006;12(6): 359–365.
25. Gibbon B, Watkins C, Barer D, et al. Can staff attitudes to team working in stroke care be improved? *J Adv Nurs*. 2002;40(1):105–111.
26. Kvarnström S. Difficulties in collaboration: a critical incident study of interprofessional healthcare teamwork. *J Interprof Care*. 2008; 22(2):191–203.
27. Chan BC, Perkins D, Wan Q, et al; for Team-link project team. Finding common ground? Evaluating an intervention to improve teamwork among primary health-care professionals. *Int J Qual Health Care*. 2010;22(6):519–524.
28. Cioffi J, Wilkes L, Cummings J, Warne B, Harrison K. Multidisciplinary teams caring for clients with chronic conditions: experiences of community nurses and allied health professionals. *Contemp Nurse*. 2010;36(1–2):61–70.
29. Goldsmith J, Wittenberg-Lyles E, Rodriguez D, Sanchez-Reilly S. Interdisciplinary geriatric and palliative care team narratives: collaboration practices and barriers. *Qual Health Res*. 2010;20(1):93–104.
30. Kuder LC, Gairola GA, Hamilton CC. Development of rural interdisciplinary geriatrics teams. *Gerontol Geriatr Educ*. 2001;21(4):65–79.
31. Delva D, Jamieson M, Lemieux M. Team effectiveness in academic primary health care teams. *J Interprof Care*. 2008;22(6): 598–611.
32. Shaw SN. More than one dollop of cortex: patients' experiences of interprofessional care at an urban family health centre. *J Interprof Care*. 2008;22(3):229–237.
33. Haggerty J, Burge F, Lévesque J, et al. Operational definitions of attributes of primary health care: consensus among Canadian experts. *Ann Fam Med*. 2007;5(4):336–344.
34. D'Amour D, Oandasan I. Interprofessionality as the field of interprofessional practice and interprofessional education: an emerging concept. *J Interprof Care*. 2005;19 Suppl 1:8–20.
35. Mills JE, Francis K, Birks M, Coyle M, Henderson S, Jones J. Registered nurses as members of interprofessional primary health care teams in remote or isolated areas of Queensland: collaboration, communication and partnerships in practice. *J Interprof Care*. 2010;24(5): 587–596.
36. Molleman E, Broekhuis M, Stoffels R, Jaspers F. How health care complexity leads to cooperation and affects the autonomy of health care professionals. *Health Care Anal*. 2008;16(4):329–341.
37. Thylefors I, Persson O, Hellström D. Team types, perceived efficiency and team climate in Swedish cross-professional teamwork. *J Interprof Care*. 2005;19(2):102–114.
38. Interprofessional Education Collaborative Expert Panel. *Core Competencies for Interprofessional Collaborative Practice: Report of an Expert Panel*. Washington, DC: Interprofessional Education Collaborative; 2011.
39. Boon H, Verhoef M, O'Hara D, Findlay B. From parallel practice to integrative health care: a conceptual framework. *BMC Health Serv Res*. 2004;4(1):15.
40. Kuehn AF. The kaleidoscope of collaborative practice. In: Joel LA, editor. *Advanced Practice Nursing: Essentials for Role Development*. Philadelphia, PA: FA Davis Company; 2004:301–335.
41. Oxford Dictionaries [homepage on the Internet]. Oxford, UK: Oxford University Press; 2012. Available from: http://oxforddictionaries.com. Accessed November 8, 2012.
42. Sheehan D, Robertson L, Ormond T. Comparison of language used and patterns of communication in interprofessional and multidisciplinary teams. *J Interprof Care*. 2007;21(1):17–30.
43. Sorrells-Jones J. The challenge of making it real: interdisciplinary practice in a "seamless" organization. *Nurs Adm Q*. 1997;21(2): 20–30.
44. Molleman E, Broekhuis M, Stoffels R, Jaspers F. Consequences of participating in multidisciplinary medical team meetings for surgical, nonsurgical, and supporting specialties. *Med Care Res Rev*. 2010;67(2):173–193.
45. Spencer J, Cooper H. A multidisciplinary paediatric diabetes health care team: perspectives on adolescent care. *Pract Diab Int*. 2011;28(5):212–215.
46. Clark PG. A typology of interdisciplinary education in gerontology and geriatrics: are we really doing what we say we are? *J Interprof Care*. 1993;7(3):217–228.
47. Mariano C. The case for interdisciplinary collaboration. *Nurs Outlook*. 1989;37(6):285–288.
48. Maslin-Prothero S. The role of the multidisciplinary team in recruiting to cancer clinical trials. *Eur J Cancer Care (Engl)*. 2006;15(2):146–154.
49. National Health Priority Action Council. *National Chronic Disease Strategy*. Canberra: Australian Government Department of Health and Ageing; 2006.
50. Northern Territory Government. *Northern Territory Chronic Conditions Prevention and Management Strategy 2010–2020*. Darwin, Australia: Department of Health and Families; 2009.
51. New South Wales Department of Health. *NSW Chronic Care Program: Rehabilitation for Chronic Disease – Volume 1*. Sydney, Australia: Department of Health; 2006.
52. Queensland Health. *Queensland Strategy for Chronic Disease 2005–2015: Framework for Self-Management 2008–2015*. Brisbane, Australia: Queensland Government; 2008.

53. South Australia, Department of Health, Statewide Service Strategy Division. *Chronic Disease Action Plan for South Australia 2009–2018*. Adelaide: South Australia, Department of Health; 2009.
54. Australian Capital Territory Department of Health (ACT Health). *ACT Chronic Disease Strategy 2008–2011*. Canberra: ACT Health; 2008.
55. Fulmer T, Hyer K, Flaherty E, et al. Geriatric interdisciplinary team training program: evaluation results. *J Aging Health*. 2005;17(4): 443–470.
56. Muir JC, Wheeler MS, Carlson J, Littlefield NW. Multidimensional patient assessment. In: Berger AM, Shuster JL, Von Roenn JH, editors. *Principles and Practice of Palliative Care and Supportive Oncology*, 3rd ed. Philadelphia, PA: Lippincott Williams & Wilkins; 2007:507–516.
57. Crawford GB, Price SD. Team working: palliative care as a model of interdisciplinary practice. *Med J Aust*. 2003;179(Suppl 6):S32–S34.
58. Ovretveit J. Five ways to describe a multidisciplinary team. *J Interprof Care*. 1996;10(2):163–171.
59. Keleher H. Why primary health care offers a more comprehensive approach to tackling health inequalities than primary care. *Australian Journal of Primary Health*. 2001;7(2):57–61.
60. Kim MJ, Cho Chung HI, Ahn YH. Multidisciplinary practice experience of nursing faculty and their collaborators for primary health care in Korea. *Asian Nurs Res*. 2008;2(1):25–34.

Terminology used to describe people who access health services

In the context of health care, there is a range of terminology used in policy, literature, media and in practice to describe people who access health services. Terminology includes patient, client, customer, expert by experience, service user, and consumer. Continuing with the concept of terminology usage discussed in the above publication, the following discussion relates to descriptors used to describe people who access health services and contextualises the researcher’s decision to use the term consumer in this thesis.

McLaughlin (2009) and Reeder (1972) contend that differing labels connote differing service provider-service user relationships, which reflect broader political and social structures. Analysis of the terms or ‘labels’ used in social work contexts, highlights that traditional use of the term ‘client’ was challenged within and outside of the social work profession in the United Kingdom (UK) (McLaughlin, 2009). Challenges centred on the imbalanced power relationship, which the term inferred; the passive client accepting and acting upon health professionals’ assessment of client needs. McLaughlin (2009) suggests that the 1979 election of the Thatcher Conservative government signalled an attack on welfare dependency and generated an overall shift from reliance on “expert knowledge and citizen passivity” (p. 1103) to an era of “‘freedom and choice’” (p. 1103). Structural changes under the Thatcher government led to market conditions in which clients became consumers or customers (McLaughlin, 2009; Mold, 2010).

Reeder (1972) uses the terms patient and client interchangeably and highlights that both terms infer passivity. According to Reeder (1972), the changing relationship of client-health care professional to consumer-health care professional is the result of three key societal changes: 1) a shift from curative to preventative type health care; 2) increased sophistication of bureaucracy and delivery of health services within bureaucratic structures and; 3) growth of consumerism as a social movement. Under these changed conditions the previously passive client becomes a consumer with bargaining power. Despite thirty-seven years between Reeder (1972) and McLaughlin’s (2009) publications, both agree that political and societal changes underpin the metamorphosis of clients to consumers, both in terms of changes to the provider-service user relationship and the terms used to describe individuals who access health services. Deber et al. (2005) suggest that the term patient connotes the same passivity that McLaughlin (2009) and Reeder (1972) attribute to the term client. Deber et al. (2005) contribute to discussions on the use of the term consumer, suggesting that it contains “objectionable overtones” (p. 346) as it implicitly infers that consumers are “the sole arbiter of [their] needs” (p. 346) and that therefore the role of health professionals is to satisfy consumers.

Although Deber et al. (2005) suggest that the term patient infers “passivity and deference to physicians” (p. 346), participants in the Canadian study preferred the term patient, albeit only moderately, to the terms client, consumer, survivor, partner or customer. Similarly, findings of more recent research studies (Loudon et al., 2012; Simmons, Hawley, Gale, & Sivakumaran, 2010) conclude that individuals accessing health services prefer the term patient. The three aforementioned research studies were conducted in tertiary (hospital), primary care and community clinics, which indicates that health service setting does not influence individuals’ preference for the term patient.

The debate around terminology used to describe people who access health services is most hotly debated in the online community. From the online community’s perspective the term patient is the preferred term and extensive use of the term patient in research publications supports the online anecdotal evidence. Loudon et al. (2012) surveyed 1428 people accessing sexual health services in five UK centres. Survey results indicated that 61% of attendees preferred the term patient to the term client, customer or user. The term patient was also the preferred term in a study conducted in an out-patient clinic and in-patient wards of a single-site mental health community service in England (Simmons et al., 2010). When asked whether they would like to be regarded as service user, patient, client, survivor or user, 72.5 per cent of respondents indicated that they would like to be regarded as patients (Simmons et al., 2010).

Sluzki (2000) suggests that “the word “patient” evokes in the public mind the complementary word “doctor”” (p. 350) and online community debates support this suggestion. Scrutiny of websites for medical associations in the UK, America, Canada, New Zealand and Australia demonstrate commitment to the term patient when referring to individuals within the context of the provider-user relationship. During data generation for this current PhD study the researcher noted that all health care professional study participants and study participants who access health services within hospital and primary care settings consistently used the term patient. Health care professional participants who provide services to individuals within community settings, and study participants who access services in this setting, used the term client.

Reviewing national health standards and/or government health department websites in the UK, Australia, Canada and the USA highlights differences in terminology usage. In the UK, the Care Quality Commission (Care Quality Commission, 2010), which oversees quality and safety health standards, uses the generic term ‘people who use services’. The Commission indicates that where the generic term relates to certain groups of people this will be specified (i.e. children, people with mental health needs) (Care Quality Commission, 2010, p. 32). In Australia, the National Safety and Quality Health Service Standards (Australian Commission on Safety and Quality in Health Care (ACSQHC), 2011) use the terms consumer and patient. The Standards define health consumers as “patients and potential patients, carers and organisations representing consumers’ interests” (p. 8) and patients as “a person receiving health care” (p. 11). The Standards state that the terms “consumer and client” are “synonyms for ‘patient’” (p. 11). Health Canada uses the terms patient and consumer throughout their website (2015), although the term patient is more prominent. Definitions for the terms were not found on the Health Canada website. The U.S. Department of Health and Human Services uses the terms patient and consumer throughout their website. In the Glossary of Terms provided on their website the term patient is defined as “an individual seeking or receiving medical care” (2015). The term consumer is not included in the Department’s glossary of terms.

Some authors (McLaughlin, 2009; Reeder, 1972) suggest that changes in political agendas underpin a shift away from use of the terms patient and client to consumer. From a political perspective, the user-provider relationship is viewed in terms of a market-based model in which buyers (consumers) purchase services from sellers (health care providers) (McLaughlin, 2009; Reeder, 1972). The consumer model of health care identifies consumers as rational beings who are able to do the following: amass information and facts relevant to their situation, identify their choices, analyse their choices and the potential consequences of each choice, and to 'buy' efficient and effect services that will meet their needs (McLaughlin, 2009). The market-based consumer-seller model, however, dichotomises the "ideal of the responsible citizen" (McLaughlin, 2009, p. 1105) against those who are financially dependent on welfare due to social circumstances. Newman (2000) refers to this approach as a search for business solutions to social problems.

Adding to the terminology debate, Frank (2004) suggests a move away from dehumanizing language such as patients, professionals, consumers and providers to use of the terms "*guests* (those needing care) and *hosts* (those temporarily in a position to offer care)" (p. 11). Plummer (2012) refers to Frank's suggestion as "the importance of remoralising the entire spectrum of relations so that people heed the others, listen to each other, and become generous" (Section 11: Para. 5). Given the differing perspectives on the constructs of service provider-service user relationships and how individuals within the relationship view themselves and the other, there is a need for all parties to critically reflect on their role and their commitment to themselves and the relationship. Frank (2004) suggests that by consumers and health care professionals changing the way they think about themselves a renewed reciprocal generosity will imbue the relationship between the two.

The above discussion of terminology used to describe people who access health care services highlights differences in terminology usage in the literature and within and between countries. In the UK, the use of the term 'people who access services' provides a neutral term that does not infer either the passivity of the term patient, as suggested in the literature (Deber et al., 2005; Reeder, 1972), nor the market-based economic inferences of the term consumer (McLaughlin, 2009; Reeder, 1972). Rather the UK's use and definition of the term 'people who access services' demonstrates a commitment to consistency of a term that is devoid of social or economic connotations.

Consumers in health care

The introduction of Engel’s bio-psychosocial model of health care in 1977 changed the way in which health care in Western health care systems was viewed. The previous doctor-driven and disease focused approach to health care shifted to consideration of the patient, the social context in which they live and the role of the doctor and the health system in supporting them (Engel, 1977). This shift in focus continued to evolve as the consumer-expert relationship progressed towards greater equality and recognition of consumers’ rights to self-determination and autonomy (Deber et al., 2005). The evolution led to the concept and terminology of patient-centred care (also referred to as consumer-centred care or person-centred care). Although Balint (1969) is credited with introducing the concept of person-centredness (de Haes, 2006; P. Duggan, Geller, Cooper, & Beach, 2006; Murtagh, 2009) the concept did not achieve significance until the landmark report *Crossing the Quality Chasm* (Committee on Quality of Health Care in America, 2001) named patient-centred care as one of six key improvements required in the US health care system. The report defines patient-centred care as “care that is respectful of and responsive to individual patient preferences, needs and values” (Committee on Quality of Health Care in America, 2001, p. 6). Other definitions take into account individuals’ “desire for information, sharing decision making and [experts] responding appropriately” (Stewart, 2001, p. 445) and extend the definition to include experts forming partnerships with consumers, their families and carers (Australian Commission on Safety and Quality in Health Care, 2012). In a review of the literature around patient-centred care, Kitson et al. (2013) identify three common core elements of patient-centred care: patient participation and involvement, relationship between the patient and the health professional and the context where care is delivered.

Central to patient-centredness is the interactional relationship between consumers and experts. A number of factors influence the relationship, not least experts’ attitudes, values and commitment to patient-centred care and consumers’ behaviour and commitment to their own care. Delivering patient-centred care requires health services to identify consumers’ preferences, needs and values. Consumer feedback surveys are a common method for health services to obtain this information. Data from surveys provides health services with information that can be used to develop strategies to improve the quality and safety of care. Cleary et al.'s (1991) national study into USA consumers' evaluation of their hospital care is considered to be the first large-scale survey to ask consumers about aspects of their care. Previously, processes of care were evaluated based on information contained within medical records. The study suggested that if health services regularly collected consumer data it would provide experts and management with valuable information to direct improvement in services and care (Cleary et al., 1991).

Patient-centred care is a component of the 'patient experience', which is defined as "the sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care" (The Beryl Institute, 2015). Measuring the quality of patient-centred care is situated within patient experience and patient satisfaction frameworks. Surveys continue to be the most common method of measuring patient experience and patient satisfaction. Patient experience questions generally require yes or no responses. For example, Did health care professionals talk to each other in front of you as if you were not there? Patient satisfaction surveys, on the other hand, ask patients to subjectively respond to questions using a rating scale.

Improving the quality of health care leads to better patient experiences, which are associated with higher levels of adherence to treatment processes, improved patient safety, decreased utilisation of health services and improved clinical outcomes (Anhang Price et al., 2014). In the UK, indicators and measures of patients' experience of health care and integrated care are incorporated into the National Health Service (NHS) Outcomes Framework 2014/15 (Department of Health, 2013). In the USA, publically available patient experience data provides consumers with information that may feed into decision-making around their choice of health care services, hospitals and individual experts. Anhang Price et al. (2014) report that there is increasing evidence that patients' experiences are improving as a result of experts and services responding positively to publically reported patient experience data.

Justification for terminology

The above discussion contextualises terminology used to describe both health care teams and people who access health care services. Although the literature suggests that people who access health care services prefer to be referred to as patient, the researcher chose to use the term consumer in this thesis because of her personal belief that the term patient suggests passivity, as discussed above in the chapter. The term expert is used in this thesis to signify all health professionals, unless the context of the text refers to, or requires health professionals to be identified specifically. The use of the term expert reflects consumer study participants overall acknowledgement of, and reliance on, the expertise of health professionals and the title of the grounded theory, *Outsiders in the experts' world*, which encapsulates the categories and sub-categories of the theory.

Chapter summary

The place of the literature review in grounded theories has been debated in the literature and this chapter provides a brief overview. In the early stages of the PhD process the researcher engaged with the literature to discern terminology used to describe health care teams and terminology used to describe people who access health services. The publication included in this chapter is a result of the researcher's engagement with the literature. Additionally, discussion on terminology usage throughout this chapter contextualise language within health and provides a background to the study's broader area of inquiry. The following chapter presents the methodological approach of the study.

PUBLICATION CONTRIBUTION

The following chapter contains a published manuscript. All authors agree to be accountable for all aspects of the published work.

Chamberlain-Salaun, J., Mills, J., & Usher, K. (2013). Linking Symbolic Interactionism and Grounded Theory Methods in a Research Design. *SAGE Open, 3*(3).

The authors agree that they contributed as follows:

Jennifer Chamberlain-Salaun

- Conception and design of the work
- Analysis and interpretation of data
- Drafting the article
- Final approval of the published version

Jane Mills and Kim Usher

- Analysis and interpretation of data
- Revising the work for important intellectual content
- Final approval of the published version

Jennifer Chamberlain Salaun 10th March 2015	Jane Mills 10th March, 2015	Kim Usher 10th March, 2015

CHAPTER 3: METHODOLOGY

> *The difference between the particularistic, routine, normative data we all garner in our everyday lives and scientific data is that the latter is produced by a methodology.*
>
> *(Glaser & Holton, 2007, para. 1)*

> *We are not scientists who claim to know where they are going. For us the journey is the inquiry.*
>
> *(Badley, 2011, p. 2)*

“Methodology is the lens a researcher looks through when deciding on the type of methods they will use to answer [their] research question, and how they will use these methods for best effect” (Mills, 2014, p. 32). The researcher chose Corbin and Strauss’ evolved version of grounded theory, which is underpinned by symbolic interactionism, as the methodological lens through which to conduct this study. This chapter presents the justification for selecting this methodology and provides an historical overview of the evolution of symbolic interactionism and grounded theory, linking both to key scholars in the respective areas. Each of the essential grounded theory methods (Birks & Mills, 2011) are explained and the publication *Linking symbolic interactionism and grounded theory methods in a research design: From Corbin and Strauss’ assumptions to action* (Chamberlain-Salaun et al., 2013a) is included in the chapter. The publication links the assumptions underpinning evolved grounded theory to the essential grounded theory methods.

Justification for the methodology

The aim of this research study was to develop a conceptual theory to explain processes of interaction between consumers and experts. In order to select the most appropriate design for the study, the researcher engaged with the literature to gain a broad understanding of key philosophies and research designs. The literature emphasises the importance of achieving congruence between the research question, the methodology and methods used in a research study (Corbin & Strauss, 2008; Creswell, 2014; Silverman, 2011a). Prior to choosing a methodological approach the researcher must decide on the research question and the desired outcomes of the research study (Dew, 2007; Mills, 2014). Although selecting a research question precedes selecting a methodology, a researcher’s beliefs and how they view the world influence the research question they will pose (Annells, 1996). For example, a researcher who believes that “reality is single, tangible and fragmentable” (Lincoln & Guba, 1985, p. 37) is more likely to pose a research question that asks ‘what’ or ‘when’ situations occur rather than ‘how’ or ‘why’ they occur. It may therefore be said, that methodology chooses the researcher rather than the contrary. As outlined in the thesis Prologue the researcher’s world view, interests, personal history and initial forays into the literature, guided the selection of the area of inquiry.

Early exploration of the literature highlighted that research studies, which consider interactions between consumers and experts, pertain to: consumers’ interactions with specific experts; interactions within particular health care settings; and/or categorise consumers according to their health condition. For example, interactions between consumers and nurses during medication activities in an acute hospital setting (Bolster & Manias, 2010), consumers with asthma in the primary health care setting (Cheong, Armour, & Bosnic-Anticevich, 2013) and women with potential compromised fertility as a result of cancer (Mathur et al., 2013). There were no studies that explored processes of interaction between consumers and experts regardless of experts’ specific professions, the setting in which consumers interacted with experts and regardless of consumers’ health conditions. This provided the justification for the study. Both the PhD proposal and funding application processes associated with this study required that a research question/s be included. The following broad research question met these requirements and guided data collection, generation and analysis: *What are the common features in processes of interaction between consumers and health professionals?*

The researcher selected grounded theory as the research methodology for this study as it is an appropriate way to examine an area of study in which there is little prior knowledge (Birks & Mills, 2011). Grounded theory does not rely on prior theoretical understandings to situate a study nor does it seek to produce a description of a phenomenon or a set of definitive findings. Grounded theory enables researchers to identify dominant processes, with the aim of developing a theory that explains what is actually going on in the area of inquiry rather than “what should, could, or ought to be” going on (Glaser, 1999, p. 840). A grounded theory will be recognisable to people familiar with internal processes relating to the substantive area of inquiry (Hunter, Murphy, Grealish, Casey, & Keady, 2011). In this study the researcher identified five dominant processes: unexpected entrance, learning a new role, establishing a presence, confronting the dichotomy of ‘us and them’, and tailored care. The integration of these processes, which in grounded theory parlance are referred to as categories, form the grounded theory *Outsiders in the experts’ world*. The grounded theory is presented in Chapter 5.

It is appropriate here to acknowledge that since Glaser and Strauss’ (Glaser & Strauss, 1967) inception of grounded theory in the 1960s it has diverged into four schools or versions: 1) classic grounded theory, which is associated with Glaser (Glaser, 1978, 1992, 1999); 2) evolved grounded theory, which is associated with Strauss and Corbin (1990, 1998) and Corbin and Strauss (2008); 3) constructivist grounded theory, which has evolved from the work of Charmaz (1995, 2003, 2005, 2006, 2014); and 4) postmodern grounded theory (Clarke, 2003, 2005). At the time of writing the journal article included in this chapter the researcher identified versions 1-3 above as the divergent schools of grounded theory. Although, at the time, the researcher was familiar with Clarke’s work, her understanding of the foundational assumptions of Clarke’s version of grounded theory was limited. The researcher has since gained a deeper understanding of the postmodernist assumptions underpinning Clarke’s work and has therefore included it as, what she considers, a fourth version of grounded theory.

The key differentiating feature of the four versions identified above, is their foundational assumptions, or the ‘lens’ through which a researcher conducts their study (Charmaz, 2014). Glaser states, “classic GT is simply a set of integrated conceptual hypotheses systematically generated to produce an inductive theory about a substantive area” (Glaser, 2004, p. 3). Although Glaser himself presents no clear foundational assumptions for classic grounded theory, Annells (1996) contends that classic grounded theory “leans ontologically towards critical realism and a modified objectivist epistemology” (p. 389) within a post-positivist paradigm. Pragmatism and symbolic interactionism underpin Strauss and Corbin (1990, 1998) and Corbin and Strauss' (2008) evolved version of grounded theory; although it was not until the 3rd edition (Corbin & Strauss, 2008) of their text *Basics of Qualitative research: Techniques and procedures for developing grounded theory* that these assumptions were articulated. For Charmaz (2014), "subjectivity is inseparable from social existence" (p. 14). Her version of grounded theory acknowledges both the researcher's subjectivity and their involvement in constructing and interpreting research data with participants. Clarke's (2003, 2005) version of grounded theory firmly embraces postmodernism. Clarke rejects a "unified system of [foundational] beliefs or assumptions" (2003, p. 555) and calls for analytically addressing meso, organisational and institutional contextual concerns (Clarke, 2005).

After extensively reading the grounded theory literature (Aldiabat & Le Navenec, 2011; Birks & Mills, 2011; Bryant, 2009; Charmaz, 2003, 2005, 2014; Corbin & Strauss, 2008; Glaser, 1978, 1992, 1999, 2004; Glaser & Holton, 2007; Glaser & Strauss, 1967; Hunter et al., 2011; Luckerhoff & Guillemette, 2011; Mills, 2009; Mills, Bonner, & Francis, 2006; Moore, 2010; Reichertz, 2010; Strauss, 1987, 1993; Strauss & Corbin, 1990, 1998; Thornberg & Charmaz, 2011; Walker & Myrick, 2006), the researcher concluded that Strauss and Corbin's evolved version of grounded theory provides congruence between the substantive area of inquiry of this study and her ontological and epistemological views of the world, which are explained in the Prologue of this thesis. Strauss and Corbin's (1990, 1998) and Corbin and Strauss' (2008) view of the place of the researcher within the research process also influenced the researcher's affinity for these authors evolved version of grounded theory. Strauss and Corbin (1994) position the researcher as the 'interpreter' of study participants "perspectives on and interpretations of their own and other actors' actions" (p.280), which the researcher integrates into their own interpretations. This view differs from that of classic grounded theory and constructivist grounded theory. The former situates the researcher as a data 'receptacle' that "collects, codes and analyses exactly [the data] he has" (Glaser, 2002, para. 2). To emphasise his point, Glaser (2002) adds that the abstract nature of a grounded theory is "independent of the researcher bias" (para. 13). Constructivists believe that the researcher and the researched cannot be separated and that it is the interaction between the two that constructs data (Guba & Lincoln, 1989). In the constructivist version of grounded theory, the researcher and the researched are ‘co-constructors’ (Charmaz, 1995, 2003, 2006). The researcher’s affinity with evolved grounded theory does not suggest that this version was prescriptively applied in this study. Committing to one version over another is not a prerequisite for using a grounded theory approach to research (Birks & Mills, 2011). Understanding and acknowledging the differing ontological and epistemological underpinnings of each version, serves to *guide not prescribe* the “systematic, yet flexible” (Charmaz, 2006, p. 2) application of grounded theory methods in this study.

Pragmatist and symbolic interactionist assumptions underpin Corbin and Strauss’ evolved version of grounded theory. Pragmatism unifies knowledge and action. Applying theory to practice distinguishes pragmatist philosophy from philosophical positions based on empirical epistemology (Charmaz, 2014; Mead, 1934; Peirce, 1934). Symbolic interactionism emphasises "that society is a process of individuals in interaction" (Charon, 2007, p. 189). The practical delivery of health care is an outcome of interactive processes between consumers and experts, which further justifies the selection of evolved grounded theory as the methodological lens through which to conduct this study. The following section of this chapter provides an in-depth description of symbolic interactionism and an overview of the key proponents of symbolic interactionism. This segues into a description of grounded theory and the essential grounded theory methods.

Symbolic interactionism

Symbolic interactionism is a sociological perspective through which to explore processes of action and interaction (Blumer, 1969; Charmaz, 2014; Charon, 2007; Corbin & Strauss, 2008; Stryker, 1987). Although, symbolic interactionism’s core beliefs may have become “increasingly muddied” (Fine, 1993, p. 64), interactionists are united in their broad acceptance of Blumer’s three premises of symbolic interactionism (Charon, 2007; Fine, 1993; Plummer, 2000b), which are:

> *Human beings act toward things on the basis of the meanings that the things have for them . . . [T]he meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows . . . [T]hese meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters. (Blumer, 1969, p. 2)*

A chronological history of symbolic interactionism highlights its intellectual precursors. They include evolutionism, Scottish moral theory, German idealism, functional psychology and American pragmatism (Manis & Meltzer, 1978; Plummer, 1996; Prus, 2003; Reynolds, 2003; Sandstrom, Martin, & Fine, 2001; Stryker, 1972). Key proponents of these philosophical and psychological traditions are included in Figure 1 with the aim of providing an overview of the chronological evolution of symbolic interactionism through to grounded theory. The influence of the philosophical and psychological traditions (Figure 1) to symbolic interactionism is discussed in the following section of this chapter.

KEY SCHOLARS	DOB / DOD	PHILOSOPHICAL / PSYCHOLOGICAL TRADITION
ARISTOTLE	DOB / DOD (unknown)	
SMITH, Adam	1723-1790	Scottish moralism
KANT, Immanuel	1724-1804	German idealism
FICHTE, Johann Gottlieb	1762-1814	German idealism
HEGEL, George W.F.	1770-1831	German idealism
SCHELLING, Friedrich W.	1775-1854	German idealism
DARWIN, Charles	1809-1882	Evolutionism
WUNDT, Wilhelm	1832-1920	German idealism
PEIRCE, Charles	1839-1914	Pragmatism
JAMES, William	1842-1910	Functional psychology; Pragmatism
DEWEY, John	1859-1952	Functional psychology; Pragmatism
MEAD, George Herbert	1863-1931	Social psychology; Pragmatism; Symbolic interactionism
COOLEY, Charles Horton	1864-1929	Social psychology
ANGELL, James	1869-1949	Functional psychology
BLUMER, Herbert	1900-1987	Symbolic interactionism

KUHN, Manford	1911-1963	Symbolic interactionism
STRAUSS, Anselm	1916-1996	Symbolic interactionism; Evolved grounded theory
GLASER, Barney G.	1930-	Classic grounded theory
CORBIN, Juliette	DOB (unknown)	Evolved grounded theory
CHARMAZ, Cathy	DOB (unknown)	Constructivist grounded theory
CLARKE, Adele	DOB (unknown)	Postmodern grounded theory

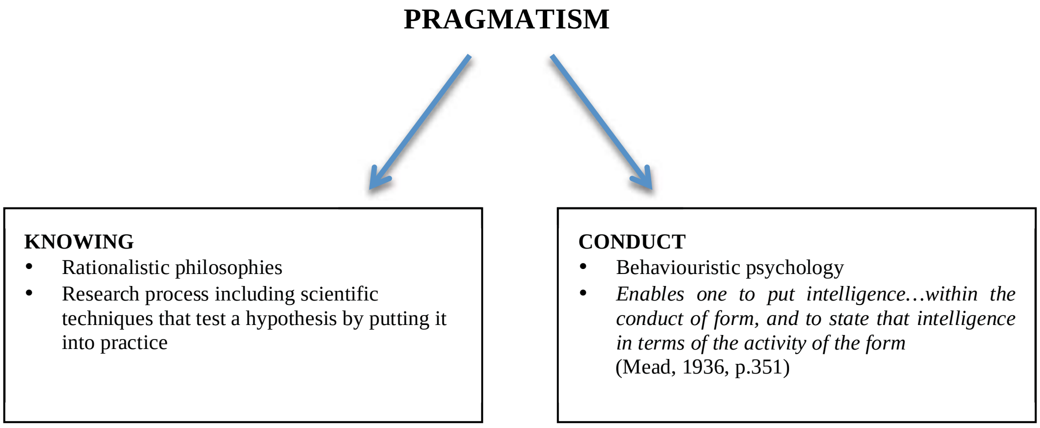
Figure 1: Key symbolic interactionists

Symbolic interactionism reflects elements of both Darwin's concept of evolution and Scottish moral theory. Reynolds (2003) highlights the precursory elements of Darwinian concepts of evolution that influenced symbolic interactionist thought: *"(1) behavior is an adaptation to environment, (2) organisms and environments are mutually determinative, and (3) life is processual and emergent by nature"* (p. 41). Scottish moral theory is also known as the common sense school of moral philosophy. Although it predates symbolic interactionism by nearly 150 years, elements of Scottish moral theory are evident in symbolic interactionism. The work of Adam Smith (1759), the exemplar Scottish moral theorist, includes the concepts of 'sympathy' and the 'impartial spectator', which Reynolds (2003) and Shott (1976) consider to be precursors to the symbolic interactionist concepts of 'taking the role of the other', 'the generalized other' and the 'I' and 'me', all of which feature in Mead's seminal work *Mind, Self, and Society* (1934).

Key elements of symbolic interactionism are also evident in German idealism and functional psychology. A key premise of symbolic interactionism is that human beings act towards 'things' based on the meaning that they ascribe to things, as highlighted above in Blumer's (1969) three premises of symbolic interactionism. 'Things' include physical objects, other human beings, institutions, guiding ideals and social situations (Blumer, 1969). Similar concepts of meaning construction feature in German idealism, in so far as human beings do not respond to the world *per se* but to their constructs of their worlds and their realities (Manis & Meltzer, 1978; Reynolds, 2003).

The era of the development of functional psychology followed that of the great German idealists. According to the functional psychologist James Angell (1907), the human mind functions and adapts in accordance with its environment. Angell's (1907) emphasises the mind's "dominantly social characteristics" (p. 87), which precede Mead's (1934) social psychology and symbolic interactionism concepts of the inseparable 'mind', 'self' and 'society'. When referring to the 'social' self, Mead (1934) refers to both the internal dialogue, which individuals conduct with themselves, and processes of interaction between individuals.

Mead, together with the scholars Charles Sanders Peirce, William James and John Dewey were all proponents of American pragmatism, which is considered to be the most prominent intellectual foundation of symbolic interactionism (Denzin, 1992; Plummer, 2000b). These previously mentioned scholars challenged the dominant rationalist and idealist philosophical theories of the late nineteenth century. Mead (1936) purported that pragmatism was "a practical sort of philosophy" (p.352), which evolved from rationalistic philosophies and a psychological approach that established 'the process of knowing [-] inside of the process of conduct' (pp. 351-352) (Figure 2).



PRAGMATISM

KNOWING
- Rationalistic philosophies
- Research process including scientific techniques that test a hypothesis by putting it into practice

CONDUCT
- Behaviouristic psychology
- *Enables one to put intelligence…within the conduct of form, and to state that intelligence in terms of the activity of the form* (Mead, 1936, p.351)

Figure 2: Pragmatism. Adapted from Mead (1936).

Symbolic interactionism evolved out of the University of Chicago (the Chicago School) and the Department of Sociology at the State University of Iowa, now called the

University of Iowa (the Iowa school). According to Meltzer and Petras (1972) the point of divergence of these two schools is methodology. The Chicago school, to which Dewey, Mead and the symbolic interactionist Herbert Blumer belong, concerns itself with a humanistic viewpoint in contrast to the scientific viewpoint associated with Manford Kuhn's Iowa school. The Chicago school is associated with methodological approaches of observation that enable an intimate understanding between investigator and participant, rather than intersubjective agreement. This provides a "nongeneralizing" (Meltzer & Petras, 1972, p. 46) understanding of human behaviour that renders society intelligible. Conversely the methodological approach of the Iowa school is associated with operationalising the key ideas of symbolic interactionism, to develop a set of generalisable patterns of human behaviour that can be empirically tested and used as predictors of social behaviour (Meltzer & Petras, 1972).

Blumer first coined "the term "symbolic interactionism" [as] a somewhat barbaric neologism" (Blumer, 1969, p. 1). Blumer (1969), however, credits his colleague and senior George Herbert Mead with developing the symbolic interactionist approach to viewing society. Mead was a social psychologist who diverged from the traditional positivist approach to psychology (Morris, 1934). Mead drew on the pragmatist ideas of Charles Peirce and William James, the psychological insights of Wilhelm Wundt, the evolutionary theory of Charles Darwin and the sociological observations of Charles Horton Cooley and James Baldwin (Sandstrom et al., 2001) to develop a social behaviourism position, which provided insights to the nature of mind, self and society (Morris, 1934). Cooley, Josiah Royce, Wundt and Wilhelm Friedrich Hegel also contributed to an early 1900s shift from an individualistic psychology to a social psychology, which incorporated mind, self and social contexts. Mead's contribution, however, went beyond that of other scholars to explain how mind and self are generated in processes of social interaction through the mechanism of language (Morris, 1934, p. xiv).

Stryker (1987) contends that the influence of symbolic interactionism declined during the 1960s and 1970s because of declines in talented researchers adopting the approach, research demonstrating use of the approach, and development of symbolic interactionism as more than "mere iteration or application" (p. 2). Contrary to Stryker's views (1987), Plummer (2000a) cites the mid-1960s as the beginning of an influential period in which symbolic interactionism helped to reshape thinking in fields of inquiry such as deviance, education and sexuality, and prompted a surge in the publication of textbooks and readers. In response to criticism of symbolic interactionism during the early 1970s, interactionists revitalised symbolic interactionism by establishing the *Society for the Study of Symbolic Interaction* and committing to hold conferences and publish newsletters and journals dedicated to the approach (Plummer, 2000a). These remain in place today.

Key tenets of symbolic interactionism are meaning and the concepts of action, interaction, self and perspectives, which are all presented and discussed in the publication included in this chapter. Another tenet of symbolic interactionism, which is significant in the context of this study, is the concept of social worlds. Early Chicago School interactionist studies focused on 'social wholes' (Clarke, 2007) in relation to encounters and interactions within shared geographic spaces or territories, for example elite neighbourhoods. By the 1950s and 1960s geographical boundaries were replaced by "culture area[s]" (Shibutani, 1955, p. 566) or "*shared discourses*" (Clarke, 2007, para. 6, italics in original), which encompass collective actors' interactions and their discourses (Clarke, 2007), with effective communication the defining boundary (Shibutani, 1955).

Social world boundaries are not rigid structures; they are "relatively fluid [and] characteristic of many worlds" (Strauss, 1993, p. 213) that "both touch and interpenetrate" (Clarke, 1991, p. 19). In the context of this research study the social world of health care encompasses the territory boundaries of early interactionists and the shared discourses of later interactionists studies. The territory boundaries of the social world of health care are defined by shared spaces in which health care is delivered, such as hospitals, general practice and community settings. Within these spaces consumers and experts act and interact in shared health and health care discourses.

Grounded theory

During the 1960s Anselm Strauss, Barney Glaser and Jeanne Quint conducted a study into experiences of dying, which resulted in a series of four monographs: *Awareness of Dying* (Glaser & Strauss, 1965), *The Nurse and the Dying Patient* (Quint, 1967), T*he Discovery of Grounded Theory* (Glaser & Strauss, 1967) and *Time for Dying* (Glaser & Strauss, 1968). In the third monograph, *The Discovery of Grounded Theory*, Glaser and Strauss (1967) explain their grounded theory method. They describe it as a method for generating and verifying social theories grounded in the data. Previously, social research had focused mainly on verifying extant theories or on testing barely generated theories. Although grounded theory was developed within the context of social research, Glaser and Strauss encouraged any researcher interested in studying social phenomena and generating theory in any field, to use grounded theory, regardless of whether they were using qualitative or quantitative data, or both (Glaser & Strauss, 1967).

The aim of a grounded theory research study is to generate a theory. Contrary to research conducted within a positivist paradigm, which deduces theory from a priori assumptions, grounded theory uses an inductive approach to research that generates theory from data (Charmaz, 2014; Corbin & Strauss, 2008; Mills et al., 2014). Research methodologies within the constructivist paradigm generally provide descriptive accounts pertaining to the area of inquiry being researched. What differentiates grounded theory from these methodologies is the research output. Grounded theory produces a conceptually abstract theory that explains, rather than describes, the substantive area of inquiry.

Regardless of the differing underlying assumptions of each version of grounded theory, as discussed previously in this chapter, the versions share a set of common methods for conducting grounded theory research. Birks and Mills (2011) define them as “essential grounded theory methods” (p. 9). Using essential grounded theory methods enables procedural rigor in a grounded theory study. Between the various versions of grounded theory there are some differences in terminology used for particular methods. As an example, Birks and Mills

(2011) use the term ‘initial coding’ whereas Glaser (1978) and Strauss and Corbin (1990, 1998) use the term ‘open coding’. Essential grounded theory methods incorporate the methods common across the differing versions and that are essential for any research study claiming to be grounded theory (Birks & Mills, 2011). The methods are: initial coding; concurrent data generation or collection and analysis; writing memos; theoretical sampling; constant comparative analysis; theoretical sensitivity; intermediate coding; selecting a core category; theoretical saturation; and theoretical integration. The publication included in this chapter describes how the methods link to the assumptions underpinning Corbin and Strauss’ (2008) evolved version of grounded theory and contextualise the methodological application of essential grounded theory methods. An overview of each method is provided below and Chapter 4: Methods, provides an explanation of how each method was applied in this study:

Initial coding and categorisation of data

Initial coding is the first step of the data analysis process. In this phase, data is scrutinised in units and labelled with a code. Units may consist of words, lines, sentences, segments or images, or a mixture of any of these (Charmaz, 2014; Rich, 2012). Through coding, data is “open[ed] up…[to] expose the thoughts, ideas and meanings contained therein” (Strauss & Corbin, 1998, p. 102). When participants’ verbatim words or groups of words are labelled, these are called ‘in vivo’ codes (Birks & Mills, 2011; Rich, 2012).

Concurrent data generation or collection and analysis

Birks and Mills (2011) use the terms ‘generation’ and ‘collection’ to differentiate respectively between data that is generated *with* and data that is collected *from* study participants. Concurrent generation or collection and analysis of data are “*interrelated processes*” (Corbin & Strauss, 1990, p. 419, italics in original) that underlay the operation of grounded theory (Glaser & Strauss, 1967). Using this method, each round of generated or collected data is analysed before the next round of data generation or collection commences. This enables theoretical sampling at each iterative round of data generation or collection.

Theoretical sampling

Theoretical sampling is a method unique to grounded theory. In quantitative research designs, sampling depends on randomly selecting statistically representative participants for the purpose of “generalization from the sample to a population and control of selectivity errors” (Patton, 2002, p. 230). In qualitative research designs, other than grounded theory, sampling generally seeks to address the initial research question and to reflect population distribution (Charmaz, 2014). The distinguishing characteristic of theoretical sampling is that it is an iterative process whereby future data collection is guided by concepts derived from analysis of data from the previous round of data collection or generation (Corbin & Strauss, 2008; Glaser, 1978; Glaser & Strauss, 1967). Theoretical sampling determines, where, how and from whom to collect or gather further data to elaborate and refine categories in the developing theory (Birks & Mills, 2011; Charmaz, 2014). Through this process, representativeness of concepts, not participants, is achieved (Corbin & Strauss, 1990). Corbin and Strauss (2008) state, “theoretical sampling begins after the first analytic session” (p. 149). Charmaz (2014) is more circumspect and recommends that researchers conduct theoretical sampling after they have “already defined and tentatively conceptualised relevant ideas that indicate areas to probe with more data” (p. 205).

Constant comparative analysis

Constant comparative analysis of data includes the use of inductive and abductive reasoning. Throughout the data collection or generation and analysis phases of a grounded theory study, data is constantly compared: “incident to incident, incident to codes, codes to codes, codes to categories and categories to categories” (Birks & Mills, 2011, p. 11). Inductive reasoning extrapolates patterns across individual data artefacts to form conceptual categories (Bryant & Charmaz, 2007a), whereas abductive reasoning “bring together things which one had never associated with one another [in] a cognitive logic of discovery” (Reichertz, 2010, para. 16).

Theoretical sensitivity

Theoretical sensitivity is an important grounded theory method. It links the researcher's creativity with the science of research (Strauss & Corbin, 1990). Theoretical sensitivity is the researcher's ability to recognise nuances in the data, to extract data elements relevant to the developing theory and to reconstruct meaning from data generated with participants (Corbin & Strauss, 2008; Mills et al., 2006; Strauss & Corbin, 1990). Theoretical sensitivity is influenced by the researcher's "personal and temperamental bent" (Glaser & Strauss, 1967, p. 46), their intellectual history and their personal and professional experiences (Strauss & Corbin, 1990). Strauss and Corbin (1990) suggest three strategies for raising theoretical sensitivity during the research process: 1) Periodically step back from the data and ask, "What is going on here? Does what I think I see fit the reality of the data?" (p. 44); "2) Maintain an attitude of scepticism" (p. 45) until all categories, theoretical explanations and questions about the data can be supported by actual data; and "3) Follow the research procedures" (p. 45). Using these suggested strategies enables researchers to creatively use their knowledge and experience during the grounded theory research process without losing sight of the "reality" (Strauss & Corbin, 1990, p. 44) of the phenomenon they are studying.

Intermediate coding

Intermediate coding is also referred to as selective coding (Glaser, 1978) and focused coding (Charmaz, 2006, 2014). It is used to connect codes and categories into more conceptual level categories using constant comparative analysis. Whereas initial coding 'opens' the data, intermediate coding connects codes and categories in conceptually abstract and even unanticipated ways (Charmaz, 2014; Strauss & Corbin, 1990). Intermediate coding does not follow initial coding in a linear process; rather the researcher moves iteratively between the two. Drawing on the metaphor *dancing with data* used by Hoare, Mills and Francis (2012) in relation to gaining theoretical sensitivity in a grounded theory study, the process of alternating between initial and intermediate coding resembles a *pas de deux* in which each dancer performs alone and together.

Selecting a core category

A core category is the overarching category that links all the categories of a grounded theory; it reassembles the parts into a whole (Birks & Mills, 2011; Corbin & Strauss, 2008). Corbin and Strauss (2008) use the metaphor of an umbrella to explain the concept of the core category. The categories, or concepts, of a grounded theory resemble the umbrella's spokes. Without the material covering the spokes, the spokes are just spokes and are of little use. The material links the spokes and gives the object form and use; it becomes an umbrella. Researchers can be assisted in identifying a core category by asking themselves how they would conceptualise their findings in a succinct way (Corbin & Strauss, 1990).

Theoretical integration

Theoretical integration of a grounded theory conceptually brings together the elements of the grounded theory process into a theory that explains phenomena (Strauss & Corbin, 1994). Theoretical integration consists of three key elements: a bank of analytical memos, saturation of major categories and a core category (Birks & Mills, 2011, p. 115). The three elements do not represent a lineal process, rather the elements are iteratively integrated. Having a bank of analytical memos provides the researcher with a documented source of their analytical thinking throughout the research study process, which can assist the researcher to saturate categories and identify a core category. Saturation of major categories means new data or further comparative analysis of data does not reveal new properties or variations in categories and that relationships between identified categories have been explained, including variations within and between the categories (Charmaz, 2014). A core category is central to the integration of a grounded theory because it encapsulates and connects all the components of a theory (Strauss & Corbin, 1990).

Storyline

Whereas once the term 'story' was used as metaphor for various types of qualitative data (i.e. interview statements, fieldnotes), it is now viewed as "concrete reality" (Charmaz, 2005, p. 526). Story provides shape and meaning to phenomena. The use of storyline as a tool for integrating a grounded theory assists the researcher to conceptually tell the story of the core category and the categories and sub-categories that it encapsulates (Corbin & Strauss, 2008). The use of storyline also provides a mechanism for presenting a grounded theory that may be otherwise "dry and unpalatable" (Birks & Mills, 2011, p. 118).

Writing memos

Memo writing is commonly linked to grounded theory methodology, although it is a valuable method in any qualitative research approach (Birks, Chapman, & Francis, 2008). Memos are theoretical, analytical or conceptual notes (Glaser, 2004; Thornberg & Charmaz, 2011) that lubricate the cogs of the ground theory research process from the planning phase through to the end of a study (Birks & Mills, 2011). To understand the multiple functions of memos Birks, Chapman and Francis (Birks et al., 2008) use the mnemonic 'MEMO' (p. 70), which consists of the following elements:

1) '**M**apping research activities'. Charon's (2007) discussion on the "Stream of Action" (p. 118-120), in the context of symbolic interactionism, provides a metaphor for memo writing. Like the stream of consciousness of a character in a Virginia Wolff novel, memos record the researcher's internal discussions and "the thinking that goes into [-] decisions and actions" (Charon, 2007, p. 119).
2) '**E**xtracting meaning from the data'. Memoing facilitates extraction of the meaning of data. Memos are "the vehicles that transport the researcher from the concrete to the conceptual" (Birks et al., 2008, p. 71).
3) '**M**aintaining momentum'. As Birks et al. (2008) point out, the fear of "making a mistake" (p. 72) can hamper researchers', particularly novices', ability to move from the process of data collection to data analysis. Memos provide researchers with the freedom to explore their own perspectives within a safe place that allows for amendments, clarifications or redundancy of thought processes (Strauss & Corbin, 1998). Memos also enable researchers to maintain research and writing momentum and to accumulate "intellectual assets" (Birks & Mills, 2011, p. 10).

4) ‘**O**pening communication’. Memos are generally for the researcher’s eyes only (Strauss & Corbin, 1998), however they also provide a mechanism for communicating ideas, generating discussion and permitting comments and input from other members of the research team or, in the case of research students, supervisors (Birks et al., 2008).

Some scholars argue that “attempts to refine the [classic grounded theory] method” (Robrecht, 1995, p. 175) focus the researcher’s attention toward procedures rather than on the data itself. The researcher contends that versions other than classic grounded theory do not emphasise procedure over data. In fact other versions of grounded theory provide an integrated systematic framework that supports researchers’ interactions with participants and the data in more fluid ways than the classic grounded theory approach. The following publication demonstrates the fluidity of Corbin and Strauss’ evolved version of grounded theory (Corbin & Strauss, 2008; Strauss & Corbin, 1990, 1998) by linking the assumptions underpinning their version to the essential grounded theory methods described above.

Publication 2

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Linking Symbolic Interactionism and Grounded Theory Methods in a Research Design: From Corbin and Strauss' Assumptions to Action

Jennifer Chamberlain-Salaun[1], Jane Mills[1], and Kim Usher[1]

Abstract

This article focuses on Corbin and Strauss' evolved version of grounded theory. In the third edition of their seminal text, *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*, the authors present 16 assumptions that underpin their conception of grounded theory methodology. The assumptions stem from a symbolic interactionism perspective of social life, including the themes of meaning, action and interaction, self and perspectives. As research design incorporates both methodology and methods, the authors aim to expose the linkages between the 16 assumptions and essential grounded theory methods, highlighting the application of the latter in light of the former. Analyzing the links between symbolic interactionism and essential grounded theory methods provides novice researchers and researchers new to grounded theory with a foundation from which to design an evolved grounded theory research study.

Keywords

grounded theory, symbolic interactionism, research design, methodology, methods

Introduction

Researchers approach the world with a set of beliefs and ideas about the nature of being (ontology), reality, and truth. This approach raises questions about knowledge and the relationship of the knower to the known (epistemology) and determines how a researcher approaches the research process (methodology) (Lincoln, Lynham, & Guba, 2011). Methodology includes the strategy and plan of action of a research study. Methods are the techniques or procedures that a researcher uses to answer their research question. Choosing which methods to use, including the recruitment and sampling of participants, data collection, data recording, data analysis, and reporting, is guided by the research methodology and the desired outcomes of the study (Crotty, 1998).

Literature aimed at postgraduate students and novice researchers reiterates the importance of researchers establishing the philosophical foundations of their study from the outset (Denzin & Lincoln, 2005). Yet this activity does not always occur. For example, in the case of grounded theory research, using the suite of grounded theory methods is often considered methodologically sufficient and due consideration is not necessarily given to a study's epistemological and ontological underpinnings. This issue is compounded by the fact that Glaser and Strauss (1967), the originators of grounded theory, did not articulate the philosophical foundation of this design. Glaser's (2004) publication states that classic grounded theory "is simply a set of integrated conceptual hypotheses systematically generated to produce an inductive theory about a substantive area" (Introduction, para.7), effectively dismissing the need for an underpinning philosophical perspective. Glaser's position, however, should not be used as a fall back that licenses a methodologically naïve approach to grounded theory research, particularly given the well-documented analysis of his position as a post-positivist researcher (Bryant & Charmaz, 2007). In contrast, Strauss (1993) and later Corbin and Strauss (Corbin & Strauss, 2008) state a number of philosophical and sociological assumptions that explicitly underpin evolved grounded theory.

In the early 1960s, Glaser and Strauss conducted a study into the experience of dying, culminating in their book *Awareness of Dying* (1965) and subsequently *The Discovery of Grounded Theory* (1967). Prior to the publication of this seminal text, social researchers were focusing on verifying extant theories or on testing barely generated theories.

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However, *Discovery* changed accepted thinking with its methods of inductive theory development.

Since the introduction of grounded theory, the methodology has diverged into three discernible schools of thought, or versions: (i) classic grounded theory, which is associated with Barney Glaser; (ii) evolved grounded theory associated with Anselm Strauss, Juliette Corbin, and Adele Clarke; and (iii) constructivist grounded theory, which stems from work by Kathy Charmaz. In this article, the authors present Corbin and Strauss' (2008) "lost chapter" and the 16 assumptions, introduce the reader to essential grounded theory methods, and provide a background to the development of pragmatism and symbolic interactionism as the epistemological and ontological foundations of evolved grounded theory. Rather than elaborating on specific features and differences between the three versions of grounded theory, the authors focus on Corbin and Strauss' 16 assumptions of grounded theory (2008; Table 1), analyzing them for key symbolic interactionist themes and their links to essential grounded theory methods. Our purpose is to highlight, particularly for novice researchers and researchers new to grounded theory, the links between the assumptions and the fundamental contribution of symbolic interactionism to grounded theory methodology and methods.

The "Lost Chapter"

Grounded theory has its roots in pragmatist philosophy and symbolic interactionist sociology (Bryant, 2009; Charmaz, 2003; Clarke, 2003; Milliken & Schreiber, 2001; Morse, 1994; Nathaniel, 2011; Schreiber, 2001; Stern & Porr, 2011; Strauss, 1987). However, until the publication of what we term the "lost chapter" in *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* (Corbin & Strauss, 2008), the influence of pragmatist philosophy and sociological symbolic interactionist theory on evolved grounded theory was not explicitly articulated by Corbin and Strauss. In Chapter 1 of the third edition of the text, the authors (Corbin & Strauss, 2008) present 16 assumptions that underpin their version of grounded theory methodology. They accompany this list of assumptions with a brief discussion on the epistemology and ontology of pragmatism and symbolic interactionism. Originally written for the second edition of *Basics of Qualitative Research* (Strauss & Corbin, 1998), the publisher originally considered this section "too complicated for a beginning text on qualitative research" (Corbin & Strauss, 2008, p. 17). Including the 16 assumptions in the latest version of the text provides the missing link that formally articulates the philosophical and sociological perspectives underlying Strauss and Corbin's evolved grounded theory methodology.

Essential Grounded Theory Methods

Grounded theory methodologies use a common "tool box" of methods in the design and implementation of a study. The following constitute this set of essential grounded theory methods: concurrent data generation or collection and analysis; constant comparative analysis; initial coding and categorization of data; intermediate coding; selecting a core category; advanced coding; theoretical integration; theoretical sampling, theoretical saturation; theoretical sensitivity; and writing memos (memoing) (Birks & Mills, 2011, p. 9). Used together, these methods constitute an unfolding, iterative process of actions and interactions that constitute the grounded theory research process (Charmaz, 2006).

In this article, we link each of the essential grounded theory methods to one or more of Corbin and Strauss' 16 assumptions (refer Table 1). Corbin and Strauss (2008) postulate that readers who familiarize themselves with their book will "easily grasp the relevance of the assumptions to [their] version of the [grounded theory] methodology" (p. 6). However, we believe "unpacking" the assumptions and their symbolic interactionist themes to explicate the links with essential grounded theory methods will clarify what it means to implement an evolved grounded theory design.

The 16 Assumptions

The assumptions are based on Corbin and Strauss' interpretation of works by John Dewey, George Herbert Mead, Herbert Blumer, and Anselm Strauss himself. All four scholars are members of a group of sociologists known as the Chicago School situated within the University of Chicago (Lutters & Ackerman, 1996). Table 2 provides a synopsis of each scholar's period at the University and highlights periods when their tenures overlapped. The Chicago School is particularly associated with qualitative methodologies, especially those using a naturalistic observational approach to the study of human group life and human conduct, such as symbolic interactionism (Blumer, 1969). A general understanding of the evolution of symbolic interactionism, and its precursor pragmatism, provides a point of departure from which to approach the assumptions and their links to essential grounded theory methods.

Pragmatism

Pragmatism is a humanistic movement in philosophy, which emphasizes the role of humans in the creation of objective and meaningful reality (Shalin, 1991). American pragmatism emerged between the 1860s and the end of World War II in the 1940s. During this period, personal material gain was driving American economic and social progress and scholars were demanding that philosophical pursuits extend beyond theory to prove their worth in practice. In a country with a meagre precapitalist past, pragmatism provided the "philosophical expression of middle class liberalism" (Novak, 1975, p. 12). The unification of knowledge and action, and applying theory to practice distinguished pragmatist philosophy from other philosophical positions, which at the time were based on empirical epistemology (Dewey, 1929).

Table 1. Linking Corbin and Strauss' 16 Assumptions With Symbolic Interactionist Themes and Essential Grounded Theory Methods (Birks & Mills, 2011; Corbin & Strauss, 2008, p. 6-8).

No.	Assumption compiled by Corbin and Strauss	Scholar and year of attributing text	Symbolic interactionism theme	Essential grounded theory methods
1	*The external world is a symbolic representation, a "symbolic universe." This and the interior worlds are created and recreated through interaction. In effect, there is no divide between external or interior world.*	Blumer, 1969	Meaning Action and interaction	Concurrent data generation and analysis Constant comparative analysis
2	*Meanings (symbols) are aspects of interaction, and are related to others within systems of meanings (symbols). Interactions generate new meanings . . . as well as alter and maintain old ones.*	Mead, 1934	Meaning Action and interaction	Constant comparative analysis
3	*Actions are embedded in interactions-past, present and imagined future. Thus actions also carry meanings and are locateable within systems of meanings. Actions may generate further meanings, with regard to further actions and the interactions in which they are embedded.*	Mead, 1934	Meaning Action and interaction	Constant comparative analysis Theoretical sampling Initial coding and categorization of data Intermediate coding Selecting a core category
4	*Contingencies are likely to arise during a course of action. These can bring about change in its duration, pace, and even intent, which may alter the structure and process of interaction.*	Dewey, 1929	Action and interaction	Concurrent data collection and analysis Constant comparative analysis Theoretical sampling Intermediate coding Advanced coding Theoretical integration
5	*Actions are accompanied by temporality, for they constitute courses of action of varying duration. Various actors' interpretations of the temporal aspects of an action may differ according to the actors' respective perspectives'; these interpretations may also change as the action proceeds.*	Mead, 1959	Meaning Action and interaction Perspectives	Constant comparative analysis Intermediate coding Advanced coding Theoretical sensitivity Memoing
6	*Courses of interaction arise out of shared perspectives, and when not shared, if action/interaction is to proceed, perspectives must be negotiated.*	Blumer, 1969	Action and interaction Perspectives	Concurrent data generation and analysis Initial coding and categorization of data Theoretical sensitivity Memoing
7	*During early childhood and continuing all through life, humans develop selves that enter into virtually all their actions and in a variety of ways.*	Mead, 1959	Action and interaction Self	Theoretical sensitivity
8	*Actions (overt and covert) may be preceded, accompanied, and/or succeeded by reflexive interactions (feeding back onto each other). These actions may be one's own or those of other actors. Especially important is that in many actions the future is included in the actions.*	Dewey, 1929	Meaning Action and interaction Self	Constant comparative analysis Memoing
9	*Interactions may be followed by reviews of actions, one's own and those of others, as well as projections of future ones. The reviews and evaluations made along the action/interaction course may affect a partial or even complete recasting of it.*	Dewey, 1929	Action and interaction Self	Concurrent data collection and analysis Theoretical sampling Theoretical sensitivity Memoing
10	*Actions are not necessarily rational. Many are nonrational or, in common parlance, "irrational." Yet rational actions can be mistakenly perceived as not so by other actors.*	Dewey, 1929	Action and interaction	Memoing

(continued)

Table 1. (continued)

No.	Assumption compiled by Corbin and Strauss	Scholar and year of attributing text	Symbolic interactionism theme	Essential grounded theory methods
11	*Action has emotional aspects. To conceive of emotion as distinguishable from action, as entities accompanying action, is to reify those aspects of action. For us, there is no dualism. One can't separate emotion from action; they are part of the same flow of events, one leading into the other.*	Dewey, 1929	Action and interaction	Concurrent data collection & analysis Memoing Theoretical sensitivity
12	*Means-ends analytic schemes are usually not appropriate to understanding action and interaction. These commonsense and unexamined social science schemes are much too simple for interpreting human conduct.*	Strauss, 1993	Action and interaction	Grounded theory as a whole process
13	*The embeddedness in interaction of an action implies an intersection of actions. The intersection entails possible, or even probable, differences among the perspectives of actors.*	Strauss, 1993	Action and interaction Perspectives	Concurrent data collection and analysis Initial coding and categorization of data Intermediate coding Memoing
14	*The several or many participants in an interactional course necessitate the "alignment" (or articulation) of their respective actions.*	Blumer, 1969	Meaning Action and interaction	Selecting a core category
15	*A major set of conditions for actors' perspectives, and thus their interactions, is their memberships in social worlds and subworlds. In contemporary societies, these memberships are often complex, overlapping, contrasting, conflicting, and not always apparent to other interactants.*	Strauss, 1993	Action and interaction Perspectives	Concurrent data collection and analysis Theoretical sampling Intermediate coding Advanced coding Theoretical integration
16	*A useful fundamental distinction between classes or interactions is between the routine and the problematic. Problematic interactions involve "thought," or when more than one interactant is involved then also "discussion." An important aspect of problematic action can also be "debate"–disagreement over issues or their resolution. That is, an arena has been formed that will affect the future course of action.*	Dewey, 1929; Strauss, 1993	Action and interaction	Concurrent data collection and analysis Intermediate coding Advanced coding Theoretical integration Memoing

Table 2. University of Chicago: Tenures of Key Scholars (M. Gibbons, personal communication, September 28, 2012).

	Position	Years	Notes
John Dewey	Position title not provided	1893-1904	Taught in the Philosophy Department
George Herbert Mead	Assistant professor	1894-1902	
	Associate professor	1902-1907	
	Professor of philosophy	1907-1931	Retired in 1931 and remained an Emeritus Professor until his death in the same year
Herbert Blumer	Attended graduate school	1923-1928	Awarded a PhD in 1928
	Instructor Associate professor Professor	1926-1952	Specific dates for each position not provided
Anselm Strauss	Student	1939-1945	Awarded a PhD in 1945
	Instructor	1952-1959	Commenced teaching 1952 (Unofficial source) Commenced teaching 1955 (Official source)

Mead (1936) considered pragmatism “a practical sort of philosophy” (p. 352), evolving from rationalistic philosophies and a psychological approach to establish “the process of knowing [-] inside of the process of conduct” (pp. 351-352). Pragmatism is considered a precursor of symbolic interactionism (Musolf, 2009; Plummer, 1996; Reynolds, 2003; Sandstrom, Martin, & Fine, 2001; Stryker, 1972).

Symbolic Interactionism

Symbolic interactionism is an empirical social science perspective on the study of human group life and human conduct (Blumer, 1969). Mead is credited with developing symbolic interactionism, although he did not use this term. Blumer explains how he himself offhandedly coined the term symbolic interactionism in a chapter he wrote for *Man and Society* (Blumer, 1937) and that it “somehow caught on and [came into] general use” (Blumer, 1969, p. 1).

The theory and conceptualization of symbolic interactionism developed during the period between the late 19th and mid-20th centuries within the Chicago School (Deegan, 2001; Musolf, 2003). Symbolic interactionists distinguish themselves from other social scientists by their shared claim to Mead and his original idea that the “human biological organism possesses a mind and a self” (Herman-Kinney & Verschaeve, 2003, p. 214). In addition, meaning and the concepts of self, action, and interaction are key interweaving themes that feature in the various interpretations of symbolic interactionism.

Reformulating the 16 Assumptions Into Themes

Meaning and the concepts of action, interaction, self, and perspectives are themes of symbolic interactionism that feature in Corbin and Strauss’ assumptions (refer Table 1). Blumer’s (1969) three premises of symbolic interaction highlight the interconnectedness of each of these themes and “sketch a picture of human society” (Blumer, 1969, p. 72):

> Human beings act toward things on the basis of the *meanings* that the things have for them . . . [T]he meaning of such things is derived from, or arises out of, the social *interaction* that one has with one’s fellows . . . [T]hese meanings are handled in, and modified through, an interpretative process used by the *person* in dealing with the things he encounters. (Blumer, 1969, p. 2)

The three themes of meaning, action and interaction, and self, together with the subtheme of perspectives are used to group the 16 assumptions, and to link them with essential grounded theory methods.

Meaning

In the first half of the 20th century, realist philosophy and psychological ways (Blumer, 1969) of accounting for the origin of meaning were particularly dominant. A realist account of the origin of meaning considers meaning as being intrinsic to all things. Thus, a hat is a hat. A psychological view of the origin of meaning contends that meaning is an expression of sensations, feelings, memories, ideas, attitudes, and motives that are brought into play in connection with a person’s perception of a thing (Blumer, 1969). Thus, a hat may be viewed as a fashion statement or sun protection. From a symbolic interactionism perspective, objects such as hats do not have an innate, permanent character; they cannot be isolated from what happens to them (Mead, 1959). Meaning arises in the process of interaction. Meaning is not fixed and immutable; it is fluid, modifiable, and open to reappraisal (Blumer, 1969; Charon, 2007; Mead, 1934; Plummer, 1996).

The process of ascribing meaning (Assumptions 2 and 3) to data corresponds to the essential grounded theory methods of initial coding and intermediate coding. Continually reassessing meanings in the data is demonstrated in the essential grounded theory methods of constant comparative analysis (Assumptions 1, 2, 3, 5, and 8). During the initial and intermediate coding phases, the researcher ascribes meaning to data through the use of codes. Ascribing meaning is not, however, an isolated act. Through the process of constantly comparing data codes to codes, codes to categories, and categories to categories, the researcher interacts with the data, continually reassessing meaning to “what is really going on” in the data (Glaser, 1998, p. 12). Assumptions 2, 3, and 5 highlight the temporal aspects of this process whereby interaction with the data changes previous meanings and generates new ones. Viewing the data in new contexts is not a matter of simply rejecting past codes and embracing new ones. It is a process in which previous codes converge into present analysis to advance the developing theory. Mead (1959) proposes that “reality exists in a present” (p. 1). In this, Mead is not referring to a single reality; rather that the present is the reconstruction of past and imagined future actions and interactions. The transformative aspect of constant comparative analysis is a unique characteristic that extends the scope of grounded theory research beyond descriptive analysis.

A unique feature of grounded theory research is the data analysis method of selecting a core category. It is the point in the grounded theory research process where previous actions, which led to the development of categories and subcategories, are aligned (Assumption 14). Until this point in the process, the researcher attributes meaning to data through the development of codes, categories, and subcategories. Comparable with the concept of locating meaning within systems of meanings (Assumption 3), selecting a core category requires the researcher to select an overarching concept that encapsulates all previously developed categories and subcategories (Birks & Mills, 2011). This process requires an intimate and distant relationship to the data and subsequent categories and subcategories. Intimately questioning the meaning of the data assists the researcher to reach a point where the grounded theory can be explained and not merely described (Corbin & Strauss, 2008). Selecting a core category also requires the researcher to stand back from the data, so that, with a wide view lens, they can isolate the common feature in all the categories and subcategories. Selecting a core category does not, however, commit meaning to an immutable state. It is a conceptually abstract representation of a range of meanings that an individual, or team of researchers, ascribes to data to explain a social phenomenon (Corbin & Strauss, 2008). Selecting a core category provides the "hook" on which to hang all other categories and subcategories.

Action and Interaction

Actions arise out of social interaction. Mead (1934) identifies two forms of social interaction: nonsymbolic and symbolic. Nonsymbolic interaction is a "conversation of gestures" (Mead, 1934, p. 167), a stimulus-response process in which individuals respond directly to one another's gestures or action (Blumer, 1969). Interaction becomes symbolic when individuals interpret and define objects and their own or another's actions and act on the basis of assigned meanings. Symbolic interaction is an interpretive process that directs the actions of the one doing the interpreting and conveys to the other, or to one's self, how he or she "is to act" (Blumer, 1969, p. 66). It is a cyclical and fluid process, in which participants continually adapt or change their acts to fit the ongoing acts of one other.

The symbolic interactionism theme of action and interaction is a feature of all the assumptions, and interacting with participants, the data, and with one's self are key activities in grounded theory research. Assumption 9 refers to the review and evaluation of actions and their influence on future actions and interactions. This assumption demonstrates the processes of interaction and action within grounded theory methods of concurrent generation or collection and analysis of data, and theoretical sampling. Concurrently generating or collecting and analyzing data requires the researcher to interact with a first round of study participants and data prior to advancing to the next stage of data collection and analysis. The results of this interactive process direct what and from whom or where the researcher will theoretically sample the next phase of data collection. Data generation, collection and analysis, and theoretical sampling are iterative processes that continue throughout the research process until a theory is fully developed.

During a course of action and interaction, contingencies are likely to arise (Assumption 4). In *Continual permutations of action*, Strauss (1993) defines two types of contingencies, external and internal, that may affect a course of action. The first are external contingencies such as economic, political, organizational, and social world conditions (Assumption 15). Being aware of external conditions that may influence an individual's actions is a consideration when undertaking concurrent data generation and analysis. When comparing data through the process of constant comparative analysis, patterns in the data relating to external conditions may become apparent. The researcher is cautioned, however, not to force the data (Glaser, 1992). Strauss and Corbin (1990) and Strauss (1993) suggest using a conditional matrix to conceptualize, discover, and keep track of conditions that influence the phenomenon being studied. During the intermediate coding phase, when categories and subcategories are developed, external conditions and their properties, such as time and place, are identified and explored. The challenge for the researcher is to explore the effects and interconnectedness of external conditions on the process of interaction and not merely to rely on conditions to provide a background for understanding the context of the phenomenon (Strauss, 1993). The effects and interconnectedness of conditions are incorporated into the advanced coding and theoretical integration stages when categories and subcategories are integrated into a grounded theory that comprehensively explains the phenomenon under study. The second type of contingency is the course of action itself. Unanticipated consequences that may arise in any course of action become consequential for pursuant acts. That is, unanticipated consequences become internal conditions in the process of interaction (Strauss, 1993).

Individuals are members of multiple social worlds and subworlds and these worlds are not without problematic interactions. Assumption 16 refers to the formation of arenas in which problematic interactions between social worlds and subworlds may be discussed, debated, and or resolved (Strauss, 1993). Clarke (2003) suggests that mapping study participants' memberships within social worlds/arenas is a useful analytic exercise that "lays out all of the *collective* actors" (Clarke, 2003, p. 559), which then provides the researcher with a view of their own and participants' affiliations within the broader social context. Understanding the broader social context provides insights into macro-level interactions that may influence individuals and groups of individuals' actions and interactions. It also provides insight into participants' arenas, which as Strauss (1993) states "are central to an understanding of 'social order'" (p. 242).

Identifying the researcher's and participants' membership of social worlds and subworlds occurs, in the case of the researcher, at the very beginning of the research process, and in the case of participants during concurrent data collection and analysis. Researchers may wish to explore their membership of social worlds through the use of memo writing. Although some researchers confine memo writing to the grounded theory stages between data collection and theory construction (Charmaz, 2003; Glaser, 1978) or see it as unique to data analysis (Corbin & Strauss, 2008), writing memos from the conceptual stages of a research study can assist researchers to identify their world-views, memberships' of social worlds, and biases. Identifying and reflecting on these elements can guide methodological decisions, thereby influencing how essential grounded theory methods are used (Birks & Mills, 2011).

Identifying participants' membership of social worlds and subworlds is most likely to occur during concurrent data collection and analysis, through the collection of demographic data and through discussions with participants in the interview process. During intermediate coding, understanding study participants' broader social contexts may assist the researcher to conceptualize how codes previously developed in the initial coding phase may relate to each other. Understanding broader social contexts also provides contextual variants, which can be included in the storyline during advanced coding and theoretical integration (Birks & Mills, 2011; Birks, Mills, Francis, & Chapman, 2009; Corbin & Strauss, 2008).

The intrinsic link between actions and emotions is emphasized in Assumption 11. Expressed emotions and feelings are often preceded or succeeded by action or inaction; they are part of the same flow of events. Recognizing these linkages is particularly important when concurrently collecting and analyzing data. Identifying participants' emotions and feelings during data collection and analysis can provide the researcher with cues as to meanings that participants ascribe to events and situations relating to the phenomena under study (Corbin & Strauss, 2008). Hoare, Buetow, Mills, and Francis (2012) explore the researcher's role in a study in which the researcher was both a participant and the researcher. The article highlights the duality of the researcher's emic, or insider, perspective and etic, or outsider, perspective. Documenting your own emotions, feelings, and associated actions, particularly in light of your emic and etic perspectives, enables you, as the researcher, to more fully explore and challenge your interpretations of the research data. This process heightens your sensitivity to the data and to the research process (Birks, Chapman, & Francis, 2008).

Self

The French anthropologist and sociologist Le Breton (2008) refers to the symbolic interactionism concept of self as "a corner stone of the conceptual edifice" (p. 62; translation by Chamberlain-Salaun).Self is central to all social acts. According to Mead (1934, 1959) self arises through social process (Blumer, 1969; Charon, 2007; Mead, 1934). Mead's concept of self differs from the accepted psychological and sociological concepts of self, dominant in the first half of the 20th century, which view self as a definitive stable entity (Blumer, 1969; Charon, 2007). Instead, Mead's self consists of the subjective "I" and the objective "me." In other words, the human being is an object to one's self and one's own actions. Self is continually constituted through reflexive processes, or self-interaction. The individual is a self-conscious being able to reflect back on itself and act toward itself as one may act toward others. The self exists for the individual insofar as the individual assumes the roles of the other (Blumer, 1969; Mead, 1959). Through taking the role of the other, one can view oneself from different perspectives and correlate these perspectives to make meaning of one's own world (Murphy, 1959). Baert (1998) refers to this as the interactionist dimension of self, whereas the symbolic dimension of self refers to the self's "dependency on the sharing of symbols, in particular language, with other selves" (1998, p. 69).

Self is implicit in all of the essential grounded theory methods. However, it is in the act of memoing and in developing theoretical sensitivity that the symbolic interactionist concept of self predominates. Similar to the stream of consciousness produced by a character in a Virginia Woolf novel, memos record the researcher's reflexive processes, the internal discussions between the "I" and "me," while providing an audit trail of "the thinking that goes into [-] decisions and actions" (Charon, 2007, p. 119). The concept of self-interaction and its influence on actions and interactions is demonstrated in Assumptions 8 and 9. As highlighted in Assumption 9, reviews and evaluations made along the action/interaction course may influence the direction or even recast the course. Recording actions, feelings, thoughts, and impressions in the form of memos preserves ideas and provides a tangible means for researchers to review the research process related to their study, including decisions made and actions taken (Birks et al., 2008; Milliken & Schreiber, 2001).

Assumption 7 draws from Mead's (1934, 1959) concept of the continually constituted reflexive self and can be linked to the essential grounded theory method of theoretical sensitivity. Theoretical sensitivity relates to a researcher's insight into themselves, others, and the area they are researching (Glaser & Strauss, 1967). It is demonstrated by a researcher's ability to recognize nuances in the data, to extract data elements relevant to a developing grounded theory, and to reconstruct meaning from data generated with participants (Birks & Mills, 2011; Corbin & Strauss, 2008; Mills, Bonner, & Francis, 2006). The act of memoing supports the development of theoretical sensitivity. It provides the researcher with a mechanism for contemporaneously recording and reflecting on their thoughts, feelings, and actions, thus providing insight into themself (Assumption 9). Similar to Mead's self, which continues to develop throughout a person's life, a researcher's theoretical sensitivity continues to develop throughout the grounded theory research process. An example of acquiring theoretical sensitivity in a grounded theory study is demonstrated in Hoare, Mills, and Francis (2012).

Perspectives

A grounded theory research process is not an objective process. Instead it is an interwoven process that integrates the phenomenon under study, with the study participants' and the researchers' perspectives and interpretations. An individual's perspective and how they interpret the world, an event or a situation, influences how they act (Blumer, 1969)

Table 3. Cross Referencing of Essential Grounded Theory Methods and Assumptions.

Essential grounded theory method	Assumption (refer Table 1)
Advanced coding	4, 15, 16
Concurrent data generation or collection and analysis	1, 4, 6, 9, 11, 13, 15, 16
Constant comparative analysis	1, 2, 3, 4, 5, 8, 15
Initial coding and categorization of data	2, 3, 6, 13
Intermediate coding	2, 3, 4, 5, 6, 13, 15, 16
Selecting a core category	3, 14
Theoretical integration	4, 15, 16
Theoretical sampling	4, 9, 15
Theoretical saturation	NA
Theoretical sensitivity	5, 6, 7, 9, 11, 13
Writing memos	5, 6, 8, 9, 10, 11, 13, 16

and this is highlighted in Assumptions 5, 6, 13, and 15. In a grounded theory study, the researcher negotiates divergent perspectives within the data to produce an integrated theory. Conscious awareness of multiple perspectives and how perspectives influence participants' and the researcher's own actions and interactions enable the researcher to build variation into data analysis, particularly during intermediate and advanced coding (Corbin & Strauss, 2008). Understanding how and why various data elements are interrelated produces a multi-factorial theory grounded in the data (Silverman, 2011). During the concurrent data generation and analysis and comparative analysis phases, perspectives must be negotiated (Assumption 6) for action and interaction to proceed. It is at the intersection of actions (Assumption 13), between generating and analyzing data, that difference among perspectives is highlighted. During initial coding and categorization of data, the researchers negotiate their own perspective of the substantive area of inquiry with that of the participant's to make meaning of raw data and assign codes. Over time and through the process of intermediate coding, in which codes are grouped together into categories, the researcher's interpretations of divergent perspectives within the data may change. Mead (1959) refers to the temporal aspect of perspectives and interpretations in Assumption 5. Constant comparative analysis of codes to codes, codes to categories, and categories to categories facilitates and indeed impels the researcher to negotiate and renegotiate perspectives to advance the developing grounded theory.

Memoing provides a means through which the researcher can make visible their internal dialogue regarding the negotiation and integration of their own and participants' perspectives (Milliken & Schreiber, 2001) and heightens the researcher's theoretical sensitivity (Assumptions 5, 6, and 13). As previously highlighted, memoing also creates a record of decision making. This may prove particularly valuable when actions within the research process are perceived, by others, as irrational (Assumption 10).

Assumption 15 draws particular attention to the influence of social worlds and subworlds membership to individuals' perspectives and therefore their interactions with others. As Strauss (Strauss, 1993) points out, memberships are often complex, overlapping, contrasting, and conflicting (Assumption 15) and therefore it is "impossible to analyze [interaction] in overly simple terms" (Strauss, 1993, p. 181). Exploring participants' and the researcher's own membership of various worlds, within the context of the phenomenon under study, may provide information about how and why membership influences individuals' perspectives and actions. This can be a valuable aspect to consider within the data when thinking about where, what, and from whom to theoretically sample subsequent data. Individual's membership of social worlds and subworlds may also provide conditional contexts when developing properties and dimensions of categories and linking categories together during intermediate coding (Birks & Mills, 2011; Strauss, 1993). However, the process of symbolic interaction cannot be simplified to a dependence on conditions such as social world memberships. Although social worlds and subworlds influence perspectives and actions, they are antecedent conditions and their value is in assisting the researcher to understand individuals' interpretive processes; they do not constitute the process itself (Blumer, 1969). The process of symbolic interaction occurs in the present when actions are interpreted and direct, adapt, and change ongoing acts.

Assumption 12

The authors agree with Milliken and Schreiber's (2012) contention that a conscious awareness and an appreciation of the influence of symbolic interactionism in grounded theory research will enhance the researcher's capacity to "develop a useful, deep, rich, explanatory theory" (p. 693). Corbin and Strauss' (2008) inclusion of Assumption 12 in their original list of assumptions highlights the complex nature of understanding human action and interaction and suggests that grounded theory, with its inherently symbolic interactionist underpinnings, is an appropriate methodology for understanding and interpreting human conduct.

Cross Referencing the Assumptions and Essential Grounded Theory Methods

Corbin and Strauss' (2008) assumptions summarize their interpretation of the works of Mead, Blumer, Dewey, and Strauss himself. This article in turn represents our interpretation of the links between Corbin and Strauss' assumptions and essential grounded theory methods and Table 3 provides a cross-referencing overview of linkages between these two elements. This cross-referencing is, however, by no means definitive and is open to alternative interpretations.

Theoretical Saturation

Theoretical saturation, which Birks and Mills include in their list of "essential grounded theory method[s]" (2011, p. 9), is the point at which categories and subcategories are well developed, continued data collection and analysis provide no significant new insights, and previously identified gaps in the theory are filled (Bloor & Wood, 2006; Corbin & Strauss, 2008; Glaser & Strauss, 1967). Theoretical saturation is not cross-referenced in Table 3, as the authors do not consider that the method aligns with any of the 16 assumptions.

Conclusion

It is important for researchers to establish the philosophical foundations of their research study from the outset. In this article, the authors unpack the 16 assumptions presented in Corbin and Strauss' (2008) "lost chapter." Unpacking the assumptions highlights the inherent symbolic interactionist themes of meaning, action and interaction, self and perspectives, and explicates their links with essential grounded theory methods. These linkages are our interpretation and are not intended as a prescription for undertaking a research study using Corbin and Strauss' version of grounded theory methodology. Rather, providing and explicating these linkages attempts to clarify what it means to conduct a research study using an evolved grounded theory approach. Awareness and an appreciation of the influence of symbolic interactionism to grounded theory methodology and methods will, we hope, ease the researcher's journey across the methodology bridge.

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References

Baert, P. (1998). *Social theory in the twentieth century*. New York: New York University Press.

Birks, M., Chapman, Y., & Francis, K. (2008). Memoing in qualitative research: Probing data and processes. *Journal of Research in Nursing*, *13*, 68-75.

Birks, M., & Mills, J. (2011). *Grounded theory: A practical guide*. Los Angeles, CA: Sage.

Birks, M., Mills, J., Francis, K., & Chapman, Y. (2009). A thousand words paints a picture: The use of storyline in grounded theory research. *Journal of Research in Nursing*, *14*, 405-417.

Bloor, M., & Wood, F. (2006). *Keywords in qualitative methods: A vocabulary of research concepts*. London, England: SAGE.

Blumer, H. (1937). Social psychology. In E. Schmidt (Ed.), *Man and society: A substantive introduction to the social sciences* (pp. 144-198). New York, NY: Prentice Hall.

Blumer, H. (1969). *Symbolic interactionism: Perspective and method*, Berkeley: University of California Press.

Bryant, A. (2009). Grounded theory and pragmatism: The curious case of Anselm Strauss. *Forum: Qualitative Social Research*, *10*, Article 3.

Bryant, A., & Charmaz, K. (2007). Grounded theory in historical perspective: An epistemological account. In A. Bryant & K. Charmaz (Eds.), *The Sage handbook of grounded theory* (pp. 31-57). Los Angeles, CA: Sage.

Charmaz, K. (2003). Grounded theory: Objectivist and constructivist methods. In N. Denzin & Y. Lincoln (Eds.), *Strategies of qualitative inquiry* (2nd ed., pp. 249-291). Thousand Oaks, CA: Sage.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London, England: Sage.

Charon, J. (2007). *Symbolic interactionism: An introduction, an interpretation, an integration*. Upper Saddle River, NJ: Prentice Hall.

Clarke, A. (2003). Situational analyses: Grounded theory mapping after the postmodern turn. *Symbolic Interaction*, *26*, 553-576.

Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Los Angeles, CA: Sage.

Crotty, M. (1998). Introduction: The research process. In M. J. Crotty (Ed.), *The foundations of social research: Meaning and perspective in the research process* (pp. 1-17). St. Leonards, New South Wales, Australia: Allen & Unwin.

Deegan, M. (2001). The Chicago school of ethnography. In P. Atkinson, A. Coffey, S. Delamont, J. Lofland & L. H. Lofland (Eds.), *The handbook of ethnography* (pp. 11-25). London, England: Sage.

Denzin, N., & Lincoln, Y. (2005). Introduction: The discipline and practice of qualitative research. In N. Denzin & Y. Lincoln (Eds.), *The Sage handbook of qualitative research* (pp. 1-20). Thousand Oaks, CA: Sage.

Dewey, J. (1929). *The quest for certainty: A study of the relation of knowledge and action*. London, England: Allen & Unwin.

Glaser, B. (1978). *Theoretical sensitivity*. San Francisco: University of California.

Glaser, B. (1992). *Basics of grounded theory analysis: Emergence vs. forcing*. Mill Valley, CA: Sociology Press.

Glaser, B. (1998). *Doing grounded theory: Issues and discussions*. Mill Valley, CA: Sociology Press.

Glaser, B. (2004). Remodeling grounded theory. *Forum: Qualitative Social Research*, *5*, Article 4.

Glaser, B., & Strauss, A. (1965). *Awareness of dying*. Chicago, IL: Aldine Publishing.

Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York, NY: Aldine de Gruyter.

Herman-Kinney, N., & Verschaeve, J. (2003). Methods of symbolic interactionism. In L. T. Reynolds & N. J. Herman-Kinney (Eds.), *Handbook of symbolic interactionism* (pp. 213-252). Lanham, MD: AltaMira Press.

Hoare, K., Buetow, S., Mills, J., & Francis, K. (2012). Using emic and etic ethnographic technique in a grounded theory study of information use by practice nurses in New Zealand. *Journal of Research in Nursing*. Advance online publication. doi:10.1177/1744987111434190

Hoare, K., Mills, J., & Francis, K. (2012). Dancing with data: An example of aquiring theoretical sensitivity in a grounded theory study. *International Journal of Nursing Practice*, *18*, 240-245.

Le Breton, D. (2008). *L'Interactionnisme symbolique* [Symbolic interactionism]. Paris, France: Quadrige/Puf.

Lincoln, Y., Lynham, S., & Guba, E. (2011). Paradigmatic controversies, contradictions, and emerging confluences, revisited. In N. Denzin & Y. Lincoln (Eds.), *The Sage handbook of qualitative research* (97-128). Los Angeles, CA: Sage.

Lutters, W., & Ackerman, M. (1996). An introduction to the Chicago school of sociology. Retrieved from http://userpages.umbc.edu/~lutters/pubs/196_SWLNote96-1_Lutters,Ackerman.pdf

Mead, G. (1934). *Mind, self, and society*. Chicago, IL: The University of Chicago Press.

Mead, G. (1936). *Movements of thought in the nineteenth century*. Chicago, IL: Chicago University Press.

Mead, G. (1959). *The philosophy of the present*. La Salle, IL: The Open Court Company.

Milliken, P., & Schreiber, R. (2001). Can you "do" grounded theory without symbolic interactionism? In R. Schreiber & P. Stern (Eds.), *Using grounded theory in nursing* (pp. 177-190). New York, NY: Springer.

Milliken, P., & Schreiber, R. (2012). Examining the nexus between grounded theory and symbolic interactionism. *International Journal of Qualitative Methods*, *11*, 684-696.

Mills, J., Bonner, A., & Francis, K. (2006). The development of constructivist grounded theory. *International Journal of Qualitative Methods*, *5*, 25-35.

Morse, J. (1994). "Emerging from the data": The cognitive processes of analysis in qualitative inquiry. In J. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 23-43). Thousand Oaks, CA: Sage.

Murphy, A. (1959). Introduction. In A. Murphy (Ed.), *Philosophy of the present* (pp. xi-xxxv). La Salle, IL: The Open Court Company.

Musolf, G. (2003). The Chicago school: In L. Reynolds & N. Herman-Kinney (Eds.), *Handbook of symbolic interactionism* (pp. 91-117). Lanham, MD: AltaMira Press.

Musolf, G. (2009). The essentials of symbolic interactionism: A paper in honor of Bernard N. Meltzer. In N. Denzin (Ed.), *Studies in symbolic interactionism* (Vol. 33, pp. 305-326). Bingley, UK: Emerald Group Publishing.

Nathaniel, A. (2011). An integrated philosophical framework that fits grounded theory. In V. Martin & A. Gynnild (Eds.), *Grounded theory: The philosophy, method and work of Barney Glaser* (pp. 187-200). Boca Raton, FL: Brown Walker Press.

Novak, G. (1975). *Pragmatism versus Marxism*. New York, NY: Pathfinder Press.

Plummer, K. (1996). Symbolic interactionism in the twentieth century: The rise of empirical social theory. In B. S. Turner (Ed.), *The Blackwell companion to social theory* (pp. 223-251). Oxford, UK: Blackwell.

Reynolds, L. (2003). Intellectual precursors. In L. T. Reynolds & N. J. Herman-Kinney (Eds.), *Handbook of symbolic interactionism* (pp. 39-58). Lanham, MD: AltaMira Press.

Sandstrom, K., Martin, D., & Fine, G. (2001). Symbolic interactionism at the end of the century. In G. Ritzer & B. Smart (Eds.), *Handbook of social theory*. London, England: Sage.

Schreiber, R. (2001). The "how to" of grounded theory: Avoiding the pitfalls. In R. Schreiber & P. Stern (Eds.), *Using grounded theory in nursing* (pp. 55-84). New York, NY: Springer.

Shalin, D. (1991). The pramatic origins of symbolic interactionism and the crisis of classical science. In N. Denzin (Ed.), *Studies in symbolic interaction* (pp. 223-251). Bradford, UK: Emerald Group Publishing.

Silverman, D. (2011). *Interpreting qualitative data*. London, England: Sage.

Stern, P., & Porr, C. (2011). *Essentials of accessible grounded theory*. Walnut Creek, CA: Left Coast Press.

Strauss, A. (1987). *Qualitative analysis for social scientists*. Cambridge, UK: Cambridge University Press.

Strauss, A. (1993). *Continual permutations of action*. New York, NY: Aldine de Gruyter.

Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Thousand Oaks, CA: Sage.

Stryker, S. (1972). Symbolic interaction as an approach to family research. In J. G. Manis & B. N. Meltzer (Eds.), *Symbolic interactionism: A reader in social psychology* (2nd ed., pp. 435-447). Boston, MA: Allyn & Bacon.

Author Biographies

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Kim Usher, Professor, is an experienced mental health nurse and researcher. She has published extensively in the nursing literature with over 100 peer-reviewed publications, book chapters and a book. Kim is a member of the James Cook University Centre for Nursing and Midwifery Research, a Fellow of the Cairns Institute and a researcher with the Queensland Tropical Health Alliance.

Chapter summary

The gap in the literature of studies that explore processes of interaction between consumers and experts regardless of experts' specific professions, the setting in which consumers interact with experts and regardless of consumers' health conditions, provides justification for this study. This chapter provides the reader with the decision-making process and justification for the use of evolved grounded theory underpinned by symbolic interactionism as the methodological approach to this study.

The development of symbolic interactionism and grounded theory are presented. The various versions of grounded theory, including key differentiating features and justification for the researcher selecting evolved grounded theory in this study are discussed. An overview of each of the essential grounded theory methods provides the reader with an understanding of how each method is used in a grounded theory study. The publication included in this chapter links the essential grounded theory methods to symbolic interactionist assumptions underpinning evolved grounded theory. The following chapter explains how the essential grounded theory methods were used in this study.

CHAPTER 4: METHOD

> *Everything that can be counted does not necessarily count. Everything that counts cannot be necessarily counted.*
>
> *Albert Einstein*

Grounded theory is both a method of inquiry and a product of inquiry (Charmaz, 2005). As a method of inquiry, grounded theory guides the generation, collection and analysis of data in a substantive area of inquiry (Charmaz, 2005) using a set of essential methods (Birks & Mills, 2011). Using the essential grounded theory methods culminates in a theory (the product of inquiry), which is grounded in the data (Birks & Mills, 2011; Charmaz, 2014; Corbin & Strauss, 2008; Strauss & Corbin, 1990, 1998). Essential grounded theory methods consist of: concurrent data generation/collection and analysis, initial coding, intermediate coding, theoretical sampling, constant comparative analysis, selecting a core category, theoretical integration, theoretical sensitivity and memo writing. How these methods were applied in this study is discussed in this chapter. This chapter commences with an overview of the ethics approval process for the research study.

Ethics

Ethical considerations were adhered to in accordance with the National Statement on Ethical Conduct in Human Research 2007 (The National Health and Medical Research Council et al., 2014). The Far North Queensland Human Research Ethics Committee (FNQ HREC) initially approved this study on the 30 May 2012 as low risk (approval number: HREC/12/QCH/59-780 LR). A modification request was submitted to the FNQ HREC in December 2012, requesting the addition of digital storytelling and non-participant observation as data collection methods. The modification request resulted in a requirement to complete a National Ethics Application Form (NEAF). The NEAF application received FNQ HREC approval 18 April 2013 (approval number HREC/13/QCH/28 – 830). Further to approval through the NEAF process, a Site Specific Assessment (SSA) application was lodged with the Research Governance Office, Cairns and Hinterland Hospital and Health Service. SSA approval was required to recruit Queensland Health employees as study participants and to conduct non-participant observation in a Queensland Health facility. Approval was granted on the 10 February 2014 (approval number: SSA/14/QCH/8 - #830). The James Cook University Human Ethics Research Committee endorsed the above ethics approvals (approval number: H5173). Figure 3 provides a list of resources developed, submitted and approved as part of the ethics approval process. Ethics approval letters are included as Appendices A, B and C.

NAME OF DOCUMENT
Information sheet – consumers
Information sheet – health care team members
Information sheet – digital storytelling workshop
Information sheet – snowball sampling: consumers
Information sheet – snowball sampling: health care team members
Informed consent form – consumers
Informed consent form – health care team members
Informed consent form - observation
Demographic Information Questionnaire – consumers
Demographic Information Questionnaire - health care team members
Promotional flyer – health Care team members participants
Promotional flyer – consumer participants
Introduction Letter – health care team member participants
Letter to health facility managers
Draft community service announcement – radio media
Draft recruitment advertisement – print media

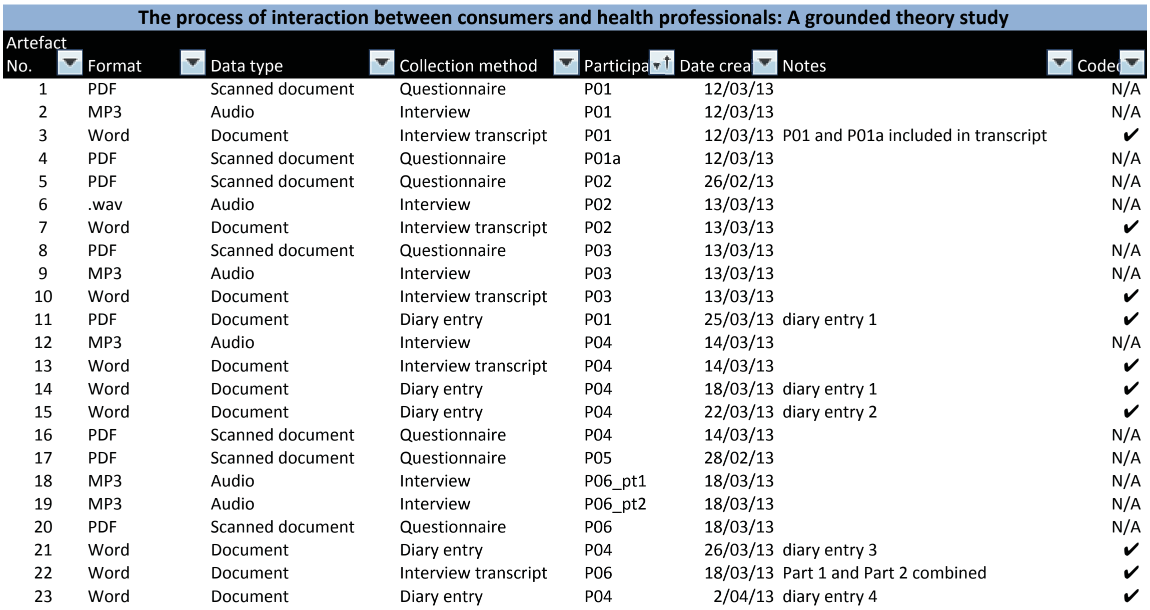
Figure 3: Documents submitted and approved by Ethics Committee

Prior to participating in the study, participants were provided with a study information sheet relevant to data collection and or generation methods and were required to complete and sign an informed consent form. Signed consent forms were scanned and electronically filed on the researcher’s password protected computer and hard copies stored in a locked cabinet. At the completion of the study signed consent forms will be archived and stored in accordance with university policy.

All study participants were provided with study information sheets prior to participating in the study. Study information sheets provided participants with information regarding the confidentiality of their information, including how any information they provided would be protected, stored and used. Additionally, study information sheets addressed the issue of participants’ anonymity. All participants, apart from those participating in the digital storytelling workshop, were assured anonymity. Due to the group nature of digital storytelling workshops, the researcher was unable to guarantee the anonymity of workshop participants and this was explained in the workshop information sheet. At the beginning of the digital storytelling workshop, the facilitator discussed the issue of confidentiality with participants. All participants provided in-principle agreement that information shared during the workshop would remain within the workshop. All previous and future research publications, reports and the PhD thesis from this research study use de-identified data. No names or information that is likely to identify participants in any way has or will be used.

Data storage and management

During the study, data records (artefacts) included: demographic questionnaires, audio interview files, interview transcripts, digital stories, participants’ diaries and fieldnotes. Individual artefacts were stored electronically on the researcher’s password protected computer under respective de-identified participant folders. The researcher developed an excel database as a mechanism for documenting all artefacts. An excerpt from the database is provided below (Figure 4). Developing and maintaining a database provided an overview of artefacts collected during the study and enabled artefacts to be sorted and filtered as required.



The process of interaction between consumers and health professionals: A grounded theory study

Artefact No.	Format	Data type	Collection method	Participa	Date crea	Notes	Code
1	PDF	Scanned document	Questionnaire	P01	12/03/13		N/A
2	MP3	Audio	Interview	P01	12/03/13		N/A
3	Word	Document	Interview transcript	P01	12/03/13	P01 and P01a included in transcript	✔
4	PDF	Scanned document	Questionnaire	P01a	12/03/13		N/A
5	PDF	Scanned document	Questionnaire	P02	26/02/13		N/A
6	.wav	Audio	Interview	P02	13/03/13		N/A
7	Word	Document	Interview transcript	P02	13/03/13		✔
8	PDF	Scanned document	Questionnaire	P03	13/03/13		N/A
9	MP3	Audio	Interview	P03	13/03/13		N/A
10	Word	Document	Interview transcript	P03	13/03/13		✔
11	PDF	Document	Diary entry	P01	25/03/13	diary entry 1	✔
12	MP3	Audio	Interview	P04	14/03/13		N/A
13	Word	Document	Interview transcript	P04	14/03/13		✔
14	Word	Document	Diary entry	P04	18/03/13	diary entry 1	✔
15	Word	Document	Diary entry	P04	22/03/13	diary entry 2	✔
16	PDF	Scanned document	Questionnaire	P04	14/03/13		N/A
17	PDF	Scanned document	Questionnaire	P05	28/02/13		N/A
18	MP3	Audio	Interview	P06_pt1	18/03/13		N/A
19	MP3	Audio	Interview	P06_pt2	18/03/13		N/A
20	PDF	Scanned document	Questionnaire	P06	18/03/13		N/A
21	Word	Document	Diary entry	P04	26/03/13	diary entry 3	✔
22	Word	Document	Interview transcript	P06	18/03/13	Part 1 and Part 2 combined	✔
23	Word	Document	Diary entry	P04	2/04/13	diary entry 4	✔

Figure 4: Excerpt from artefacts database

Computer assisted qualitative data analysis systems are a useful tool to manage data and to support data analysis processes. They are not, however, a substitute for the researcher conducting data analysis and developing theory in grounded theory studies. The researcher's initial attempts at using NVivo software in this grounded theory study were quickly aborted. The researcher considered that learning and attempting to feel confident with an unfamiliar software program, in the middle of a PhD, was not a constructive use of her time. Instead, the researcher chose to use a process developed by Hahn (2008) to manage data. Hahn's process uses Microsoft® Word and Excel to code, sort and retrieve data. The researcher had used Hahn's (2008) method in previous research projects and had made numerous minor adaptations to the method as required.

Using Hahn's (2008) method, the researcher developed data identification formats for the purposes of data retrieval and presentation of direct data quotes, particularly in Chapter 5: Findings. Each artefact was allocated an 'A' for 'artefact' followed by the artefact number as indicated on the database (Refer Figure 4). Data from interview transcripts include a row number as signified by the letter "r". Quotes from interview transcriptions are therefore displayed in the following format, i.e. A13r177. Audio files, which were not transcribed, include digital stories and interviews with experts. These data collection and generation methods were conducted towards the end of this phase of the study, for the purpose of theoretically saturating categories. The researcher listened to audio soundtracks many times during constant comparative analysis processes and transcribed and coded excerpts of raw data into Microsoft® word and excel documents. For the purposes of data retrieval, the researcher labelled these data sources with the artefact number and the time point in the audio file at which the data excerpt commences. For example A16_21:04. For the purposes of identifying direct quotes from audio files in Chapter 5: Findings, the artefact number only is used. Fieldnotes are identified by the artefact number only for the purposes of retrieval and presentation. An example of data identification formats is provided in Figure 5. Data coding processes are described in more detail later in this chapter.

Artefact number	Data type	Collection method	Data identification example
7	Document	Interview	A7r15
19	Audio file	Interview	A19_00:35
67	Fieldnotes	Observation	A67

Figure 5: Data excerpt identification

Engaging with the literature

A formal review of the literature in the substantive area of inquiry is not generally included in a grounded theory study. A discussion of the place of the literature in grounded theory studies is presented in Chapter 2: Background. Suffice to say here that researchers are not immune to the literature prior to commencing a PhD program. Critically reflecting on prior knowledge, experience and preconceptions is important however, and enables researchers to remain open to the data and the developing theory in their grounded theory studies (Birks & Mills, 2011; Charmaz, 2014). Prior to commencing the PhD program the researcher had engaged with health literature during research projects that she undertook through James Cook University-Primary Health Care Research Evaluation and Development fellowships and during research projects that she had undertaken as part of her role as a Research Assistant at James Cook University.

Prior to commencing data collection and generation for this grounded theory study the researcher engaged with the literature without focusing on the substantive area of inquiry. This process assisted the researcher to develop a background to the study for the purposes of a formal proposal for enrolment into the PhD program and for funding application submissions during the study. Additionally, in the early stages of the study, the researcher examined the literature around terminology used to describe health care teams. This linked to the initial aim of the research study, which was to explain the process of interaction between consumers and health care teams. The researcher's purpose for reading the literature about this topic was to gain a clearer understanding of the meanings and usage of terminology to describe health care teams. Examining this literature raised the researcher's theoretical sensitivity about this topic, particularly in relation to inconsistencies in language used to describe health care teams, and resulted in the publication *Terminology used to describe health care teams: An integrative review of the literature,* which is included in Chapter 2. It became evident to the researcher, during early rounds of data collection and generation, that the concept of health teams was virtually non-existent in practice for consumer participants in this study. Consumer participants did not consider that teams of health professionals were treating them. Consumers viewed health professionals as individual practitioners who may or may not interact with other experts.

Engaging with the literature throughout the early stages of the study also raised the researcher's theoretical sensitivity to the use of terminology used to describe people who access health services. When deciding to use the term consumer in this study, the researcher was influenced by the use of the term consumer in Australian Government documents (Australian Commission on Safety and Quality in Health Care (ACSQHC), 2014; National Health and Hospitals Reform Commission, 2009) and her personal belief that the term patient infers a passive recipient of health care services. After developing the resultant grounded theory of this study, the researcher returned to the literature for the purposes of situating key findings from the theory within "a theoretical body of knowledge" (Birks & Mills, 2011, p. 12), which provided the basis for Chapter 6: Discussion. Returning to the literature after generating the grounded theory also enabled the researcher to view the literature more critically for the purposes of strengthening the background chapter of the thesis (Chapter 2).

During the first year of the research study process the researcher read texts and journal articles about both symbolic interactionism and grounded theory with the aim of increasing her knowledge and understanding of both. Engaging with the literature about these methodologies/methods and engaging with the health literature, as outlined above, informed the research process and the resultant grounded theory product (Charmaz, 2014; Thornberg & Charmaz, 2011).

Sample

Demographic questionnaire

A total of thirty-two participants were recruited to the study and there were more female participants than male participants (Figure 6). Participants included twenty-three consumers and nine health experts. Demographic questionnaires were completed by twenty-four study participants. The eight participants, who did not complete demographic questionnaires, consisted of six consumers and two health experts. These participants were recruited via snowball sampling and participated in observation sessions only. Provision for the collection of demographic information from participants recruited via snowball sampling was not included in the ethics application. In retrospect, this is a limitation of the study.

Information collected via demographic questionnaires demonstrated that participants ranged in age, with the majority of participants being in the 35-44 year old age group (Figure 7). Demographic questionnaires also demonstrated a diversity in consumer participants’ health conditions, which included: epilepsy, hypothyroidism, down syndrome, psychological or psychiatric conditions, asthma, cancer, quadriplegia, complex migraine, inflammatory arthritis, sciatica, chronic neck pain, osteoporosis and Alzheimer.

Gender	Demographic questionnaires completed N=24		Demographic questionnaires not completed N=8	
	Consumers N=17	Health experts N=7	Consumers N=6	Health experts N=2
Female	11	7	3	1
Male	6	0	3	1

Figure 6: Study participants' gender by participant type

	Demographic questionnaires N=24	
Age group	Consumers N=17	Health experts N=7
19-24	1	1
25-34	0	1
35-44	6	1
45-54	3	1
55-64	5	0
65-74	1	1
Incomplete	1	2

Figure 7: Study participants' age group by participant type

Sampling

Maximum variation sampling, theoretical sampling and snowball sampling were used to recruit participants to this study. Patton (2002) categories these strategies under the generalised heading of "purposeful sampling" (p. 243). The underlying principle of purposeful sampling is selecting information-rich cases, texts or settings from which researchers can garner in-depth information relating to the purpose of the study (Patton, 2002; Rapley, 2011; Sandelowski, 2000).

Maximum variation sampling

The aim of purposefully recruiting a wide range of participants was to enable identification of common patterns in the data that cut across variations (Patton, 2002). Initial rounds of sampling aimed to recruit a maximum variation sample representing health consumers across a range of age groups and with a wide range of health conditions. With this in mind, advertising for consumer study participants through local print media was broad. Advertising avoided targeting consumers with specific health conditions and asked more broadly for consumers or carers who accessed a range of health professionals. This resulted in recruitment of consumers across age ranges (Figure 7) and with a range of health conditions as previously mentioned (refer *Demographic questionnaire* paragraph above).

Strategies for recruiting health expert study participants included: dissemination of advertising flyers to four general practice clinics in Cairns, the city in which this study was conducted, and distributing study flyers to three public hospital wards for which site specific assessment approvals had been obtained. Additionally, the researcher attended staff meetings at each of the three hospital wards to explain her study. Using these strategies resulted in recruitment of six experts from two wards at the public hospital and one expert from a general practice. These experts were in addition to the two experts previously recruited through snowball sampling. An overview of participants per profession is included in Figure 8.

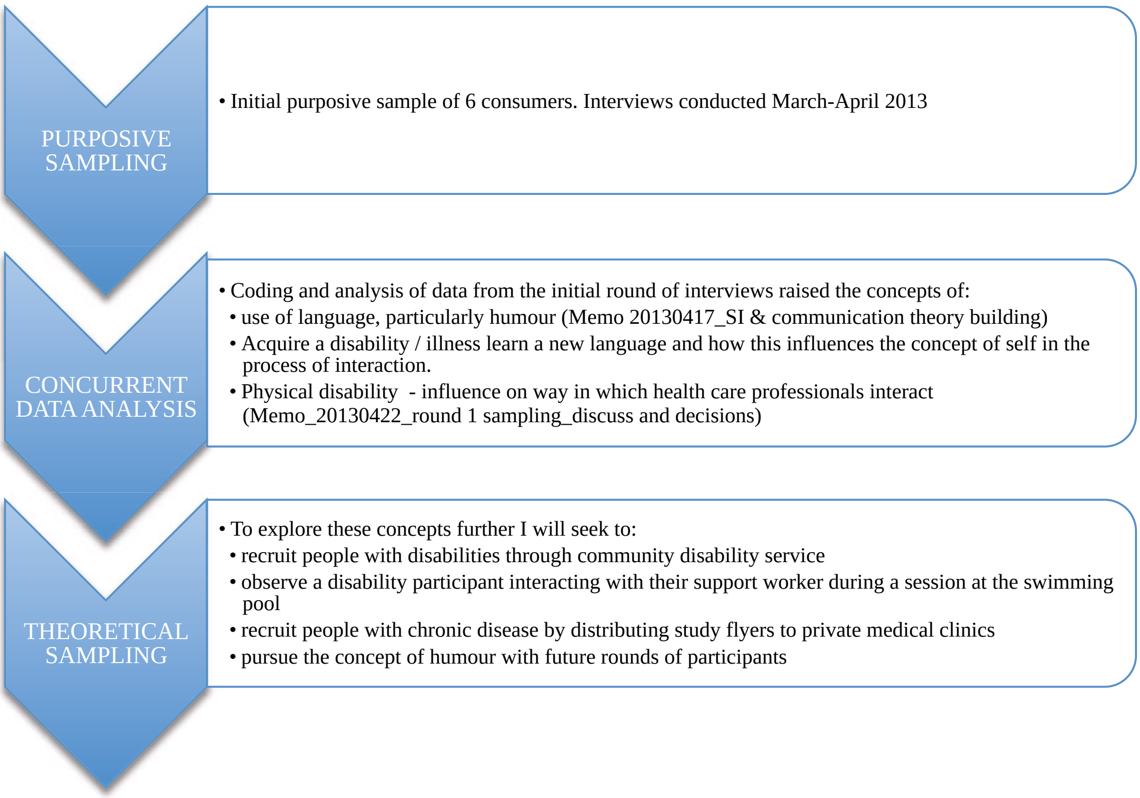
Health expert participants N=9	
Profession	**Number of participants**
Nurse	4
General practitioner	2
Support worker	1
Social worker	1
Aboriginal Health Worker	1

Figure 8: Health experts by profession

Theoretical sampling

Theoretical sampling guides decisions about from who, what, where or how to collect or generate the next round of data (Birks & Mills, 2011; Patton, 2002; Strauss & Corbin, 1998). Charmaz (2006) asserts that theoretical sampling is only of value once categories have been developed. Birks and Mills (2011), on the other hand, contend that theoretical sampling is of value from the very first data collection or generation and analysis event, as concepts begin to take shape even during the early stages in the grounded theory research process. In later stages of the research process, theoretical sampling is a valuable method for addressing gaps in the developing theory.

The initial purposive round of concurrent data generation and analysis generated codes around concepts of physical disability and how a person's health condition influences the way experts interact with consumers. Based on initial codes and concepts the researcher decided to theoretically sample people with disabilities and or carers/parents of children with disabilities to pursue the concepts further. Focused strategies to recruit consumer participants based on theoretical sampling decisions included: redistributing flyers to community organisations that deliver services to this client group, offering to address a group of carers and support workers from a key community organisation and approaching previous study participants asking them to refer potential participants. These strategies elicited one additional participant. The researcher documented the theoretical sampling decision making process at the time and this is presented in Figure 9.



- Initial purposive sample of 6 consumers. Interviews conducted March-April 2013

- Coding and analysis of data from the initial round of interviews raised the concepts of:
  - use of language, particularly humour (Memo 20130417_SI & communication theory building)
  - Acquire a disability / illness learn a new language and how this influences the concept of self in the process of interaction.
  - Physical disability - influence on way in which health care professionals interact (Memo_20130422_round 1 sampling_discuss and decisions)

- To explore these concepts further I will seek to:
  - recruit people with disabilities through community disability service
  - observe a disability participant interacting with their support worker during a session at the swimming pool
  - recruit people with chronic disease by distributing study flyers to private medical clinics
  - pursue the concept of humour with future rounds of participants

Figure 9: Theoretical sampling decision making example

Snowball sampling

Snowball sampling identifies information rich informants who can access or suggest additional study participants. Through this process the ‘snowball’ gets bigger as new information is accumulated (Patton, 2002). Theoretically sampling six health experts resulted in snowball sampling of six additional consumers. These consumers consented to the researcher observing interactions between them and their health experts. All observation sessions occurred in the hospital. Additionally, two consumers who were recruited in the first sampling round of the study, snowball sampled one health expert each. This resulted in the researcher observing interactions between one consumer and their general practitioner in a general practice setting and observing interactions between a consumer and their carer in a community setting.

Theoretical saturation

Theoretical saturation refers to the point in data analysis when categories are conceptually well developed and further collection or generation and analysis of data yields no new properties or insights about the categories or the developing grounded theory (Charmaz, 2014; Corbin & Strauss, 2008; Morse, 2004; Strauss & Corbin, 1990). As Wiener (2007) states, however, “Theoretical saturation is [a] judgement” (p. 306), which may also be influenced by lack of time and/or money (Strauss & Corbin, 1998). Theoretical saturation is an aim and a consequence of constant comparative analysis and theoretical sampling (Charmaz, 2014; Holton, 2007).

Data analysis guided theoretical sampling and theoretical sampling guided data analysis until the final categories of this grounded theory were integrated into a whole, which resulted in the grounded theory *Outsiders in the experts’ world*. Judging the point at which to stop theoretically sampling participants is a fine line. Thorne and Darbyshire (2005) caution researchers against a false claim that “no new information will arise from further sampling”, which they refer to as the “wet diaper” (Thorne & Darbyshire, 2005, p. 1108). In this study the researcher made the opposite, but equally false claim that ‘further sampling was necessary to garner new information’, which she refers to as the ‘dry diaper’.

As a novice, the researcher was eager to continue theoretically sampling new participants in the hope of getting ‘more data; the right data’ to achieve theoretical saturation of categories. The principal supervisor’s advice to return to the data, instead of back into the field, prompted the researcher to return to the data and engage more intentionally with the process of constant comparative analysis. Returning to the data, at that point, enabled the researcher to ‘view’ the data in new ways and to generate new meanings that provided depth to categories and subcategories. Decisions around further theoretical sampling and judgments around saturation points were therefore better informed than falsely claiming ‘wet or dry diapers’.

Theoretical sensitivity

Theoretical sensitivity “is an acquired skill that does not come easily or naturally” (Bryant & Charmaz, 2007b, p. 17). It relates to a researcher’s insight into themselves, others and the area they are researching, and their ability to make use of that insight throughout the grounded theory research process. A researcher’s level of insight is influenced by their “personal and temperamental bent” (Glaser & Strauss, 1967, p. 46), their intellectual history and their own and others’ experiences. The ability to recognise nuances in the data, to extract data elements relevant to the developing theory and to reconstruct meaning from data, reflects a researcher’s theoretical sensitivity (Birks & Mills, 2011; Corbin & Strauss, 2008; Mills et al., 2006). The remainder of this section presents examples of ways in which the researcher’s theoretical sensitivity was raised and how this influenced the research study process.

The researcher gained further personal insight early in the research study process by completing Birks and Mills’ Activity 1.1 (2011, p. 9). The activity provided the researcher with an opportunity to explore and clarify her own worldviews, which raised her theoretical sensitivity about the position of the researcher and the nature of reality. The researcher identified that, in her view, researcher and participants construct reality through their interactions during interviews. This reality then evolves as the researcher analyses the data from their own perspective at the point in time of analysis. The researcher concluded from completing the activity, that the researcher’s role is not to speak on behalf of participants but to interpret participants' stories to create a new story, which will be 'more than the sum of its parts'. Acknowledging and understanding these views influenced the researcher's selection of methodology and methods for conducting this study.

Engaging with the symbolic interactionism (SI) literature also raised the researcher's theoretical sensitivity to nuances in the data. The following excerpt form a memo written 15 July 2013 describes the influence of the SI literature on the researcher's theoretical sensitivity. The memo has not been amended except to include formatted referencing of a particular book referred to in the memo:

> *I had a general understanding of the concept of the 'looking glass self', which, from memory, originated in the work of the Scottish moralist Adam Smith (need to verify this). Adam Smith was 'impartial spectator'. Mead developed the concept further as 'taking the role of the other' and it is extensively written about / referred to in the SI literature. When I interviewed P07 and started coding the interview transcript (A32) I did not 'hear' or 'see' the segment of data that I have now coded as "not seeing oneself" (r244). But it is there in the data.*
>
> *Since my initial interaction with the data I have read Em Griffin (2012) (Chapter 5). Returning to A32 to complete my initial coding of the interview transcript the segment of data and the code seem so obvious. So did I just miss it on the first reading? Was I tired / unfocused? Was it my lack of theoretical sensitivity at that point in time? Given the amount of SI literature I have read, I question this last point. Yet maybe Goffman explained it in such simple terms that the dots just joined for me and produced an 'ah ha' moment!*

To clarify a point in the memo, the concept of the 'looking glass self' was developed by Charles H. Cooley (1956), which was preceded by Adam Smith's (1759) concept of the 'impartial other'. The initial code, "not seeing oneself" (A32r244), which is referred to in the memo above, was integrated into the grounded theory of this study through the process of constant comparative analysis. It was integrated into the category *Unexpected entrance* under the sub-category *Changing perceptions of self.*

Writing memos

Of all the essential grounded theory methods, writing memos is the most important as it plays a central role in developing grounded theories (Birks & Mills, 2011; Charmaz, 2014; Montgomery & Bailey, 2007). Birks (2012) highlights the fundamental centrality of memoing in the grounded theory research process. Memoing provides a means for researcher’s to record their ideas about the developing theory and their reflections and interpretations of events and the research process. Memo records also provide an audit trail of decision-making in the grounded theory process. In this study, the researcher started writing memos from the very early conceptual stages of the research study and continued memoing throughout the entire research process. The researcher developed a naming and electronic filing system to ensure easy access to memos.

Memo formats included electronic, hand written and voice recordings on a mobile phone. The latter two formats were subsequently converted to electronic formats, to ensure consistent storage of memos and ease of access. The researcher heeded suggestions to categorise memos (Birks et al., 2008; Charmaz, 2014; Strauss & Corbin, 1990, 1998) and labelled memos with the date, using the format yyyymmdd, combined with a descriptive title i.e. 20131005_position of researcher. Formatting the date as indicated ensured that memos were electronically filed in chronological order, which provided the researcher with a timeline of her thoughts, ideas and analysis throughout the research process. As the research study progressed and the thesis developed, the researcher created separate electronic folders for each chapter of the thesis and for key activities and/or processes within the study. Memos were subsequently filed according to their relevance to each chapter or activity. Using this system to file memos provided easy access, particularly when writing specific chapters and sections of the thesis. During the course of the study, the researcher produced approximately 120 memos ranging in length from one paragraph to three pages of typed text.

Writing memos throughout the research study provided the researcher with a bank of memos, which assisted in the theoretical integration of the grounded theory in the final stages of the grounded theory process. Additionally, writing memos raised the researcher's theoretical sensitivity to nuances and meanings in the data. The following memo, which the researcher wrote on 17 April 2013, captures both. The memo is included here in its original format, although references have been correctly formatted for the purposes of presentation here:

> *Have just read Denzin's article titled "Emotion as lived experience" (1985). The article raises my awareness around my lived experience of emotion during the participant interviewing process, so far, in my study. Whilst I was already conscious of my experiences of emotionality during interviews, the article helped me to clarify those experiences and to bring reflective, interpretive meaning to them.*
>
> *Plessner (1970) describes the three-fold relationship with one's body, as follows, "he is his body, he is in his body, and he is outside his body" (p. 35-36). The body in turn experiences the three-fold structure of emotions as "a sense of feeling, a sense of self feeling the feeling, and a revealing of the interactional meaning of the feeling to the self" (Denzin, 1985, p. 225). On two occasions, whilst interviewing participants, tears welled in my eyes. At the time, I sensed a feeling and had a sense of myself feeling a feeling, which physically expressed itself as tears. It was only, later, when I read Denzin's article that I delved into the deeper aspects of what those feelings meant.*
>
> *The tears were not only an emotional response to the story I was being told but were also in response to the emotions that the participants were expressing (they too had tears in their eyes). In this instance our roles as researcher and researched became obsolete; for just that moment in time we were two people, almost strangers, connecting through a shared emotional experience.*
>
> *On both occasions the recounts being told were stories about acts of human kindness. So why is it that acts of human kindness bring tears to people's eyes? In one story a mother related to me how a general practitioner had shown respect and kindness to her intellectually disabled son by placing him at eye level and speaking directly to him, instead of speaking to her. The other story was told by a disabled*

> *participant and related to the actions of an unknown women paying for his grocery shopping one time when the credit card machine at the supermarket was not working and he had no cash with which to pay. Both participants spoke of not being used to receiving, or in the case of the mother, witnessing such acts of kindness.*
>
> *If I consider the meaning of the feelings that I experienced I would say that I felt sadness, pain and joy by the generosity that people had shown these participants. Sadness, because I recognised that all too often people, myself included, are so caught up in the routine and busyness of life that we do not take the time to give of ourselves generously and with kindness. Pain that these participants have experienced as a result of a disability, which they did not ask for and joy that these study participants, who confront living with disability on a daily basis, had been humble recipients of such acts of kindness.*
>
> *Are the emotions that we experience, filtered through pre-existing meanings (Denzin, 1985) that we associate with having a disability and how people interact with those who have a disability?*
>
> *The fact that these participants were not used to receiving acts of kindness raised questions that I wish I had asked. I wonder why they are not used to receiving or witnessing such acts of kindness. Is it because they feel less worthy of kindness because they/their child has a disability? Is it because they are used to being treated with less than kindness because they have a disability? Are people less likely to demonstrate kindness to someone with a disability because of the fear of it being interpreted as pity?*
>
> *Is receiving kindness difficult for most people or more difficult for those with a disability?*

Methods of data collection and analysis

In *Discovery of Grounded Theory* (Glaser & Strauss, 1967), the authors suggest using a range of methods for collecting or generating data. Since the publication of the text, interviewing has tended to become the favoured method for collection or generating data in grounded theory studies. More recently, Silverman (2011b) returns to Glaser and Strauss' original suggestion and contends that using a range of data collection and generation methods contributes to the quality of a grounded theory study.

Using a range of data generating methods requires the researcher to negotiate a range of perspectives. During interviews the researcher and the participant interact with each other to generate data that incorporates both actors' perspectives. Participant diary entries on the other hand, capture the participants' perspectives only and researcher observations capture the researcher's perspective. In all instances the researcher then analyses the data from their own perspective. In this study the researcher used the following date collection and generation methods: demographic questionnaires, interviews, participants' diary entries, digital storytelling, observation and fieldnotes.

The process of concurrently collecting or generating and analysing data is a unique feature of grounded theory methods (Birks & Mills, 2011). Generating data refers to the process of generating data *with* participants via methods such as interviews or focus groups. Data collection refers to collecting artefacts *from* participants or *from* other sources such as: participants' diaries, photos, newspaper articles, demographic questionnaires or blog entries. In most research approaches, other than grounded theory, data is generated and/or collected prior to data analysis. In a grounded theory study, concurrent data generation or collection and analysis are, as the name suggests, a concomitant process.

The researcher used a range of data collection and generation methods in this study, including: demographic questionnaires, interviews, consumer diaries, digital storytelling and observations. An overview of the type and number of participants involved in providing and generating data and the quantity of data produced is presented in Figure 10. Including a variety of data collection and generation methods reflects Glaser and Strauss' (1967) assertions that "different kinds of data give the analyst different views or vantage points" (p. 65). Through the process of concurrent data collection and analysis, codes and categories were developed, refined, saturated and integrated into the resultant grounded theory.

Data generation/collection method	Consumers	Health experts	Total participants	Quantity of data
Demographic questionnaire	17	7	24	24 questionnaires
Interview	10	7	17	17 transcripts
Consumer diaries	3	0	3	20 entries
Digital storytelling	7	0	7	6
Observation	8	5	13	7 hours of observation and 18 A4 pages of fieldnotes

Figure 10: Study participants per data collection/generation technique and data output

Interviews

Interviews are the most common method of generating data in qualitative studies (M. Cleary, Horsfall, & Hayter, 2014) and are the most common source of data in grounded theory studies (Birks & Mills, 2011). They provide a mechanism for understanding meanings that participants' attribute to their experiences and their social worlds (Miller & Glassner, 2011). The researcher conducted interviews with seventeen study participants (Figure 10). Interviews consisted of fifteen face-to-face interviews (one interview was conducted with two consumer study participants) and one telephone interview. Interviews were conducted in participants' own homes or in a private, quiet room at the researcher's university. The average duration of interviews was 1 hour 10 minutes with consumers and 32 minutes with health experts. All interviews were audiotaped. Interviews with consumers were professionally transcribed verbatim. Interviews with health experts were conducted as the final round of data generation and were not professionally transcribed. Rather, the researcher elected to listen to them numerous times and to intermediately code them to saturate categories in the advancing grounded theory. Intermediate coding and data saturation methods are discussed in more detail below.

Researcher and study participant enter into the interview process each with their own intent, which in some instances may differ. The researcher's intent during interviews conducted as part of this study, was to explore participants' experiences of interacting respectively with health experts and consumers. All interviews commenced with the researcher introducing herself by way of an overview of her qualifications, work experience and research history. After conducting and reflecting on the first three interviews, the researcher believed that it was also important to provide participants with a brief overview of the grounded theory research process prior to commencing interviews. The aim of this was to explain the informal interview process to participants. As the researcher became more experienced in conducting interviews, and following her reading of Richardson and St. Pierre (2005), she was prompted to also outline the resultant product of the research process to participants. The reasoning behind this fits with the researcher’s epistemological views of her position as researcher/interpreter, which is congruent with an evolved version of grounded theory (Corbin & Strauss, 2008; Strauss & Corbin, 1990, 1998). The researcher explained to participants that the resultant grounded theory from the study would transcend their voices and would represent her analysis and interpretation of data. This point was very pertinent. During the first round of interviews, the researcher sensed that some consumer participants had an ‘axe to grind’ with health experts and/or the health system and that perhaps they perceived this study as an avenue to voice their discontent. It was therefore important as a researcher conducting a grounded theory study, to explain to participants that the resultant grounded theory would “go beyond description to a transcending bigger picture” (Glaser, 2002, p. 25) of processes of interaction between consumers and health care teams.

During the first round of data generation the researcher conducted four unstructured interviews with consumers. The interviews opened with the “‘grand-tour’ question” (Mills, 2014, p. 37), ‘Can you tell me about your experiences of interacting with health care professionals?’ The interview progressed based on participants’ responses. Unstructured interviews do not reflect preconceived ideas or theories and are beneficial when virtually nothing is known about the area of inquiry and/or the researcher is seeking depth of information (Gill, Stewart, Treasure, & Chadwick, 2008).

Further rounds of consumer interviews also opened with the grand-tour question presented above but then followed a more semi-structured interview format. Through the process of constant comparative analysis of data, the researcher was sensitive to information in participants' stories that related to codes and categories previously identified in the developing grounded theory. As participants touched on areas of interest to the developing theory, the researcher posed questions that invited participants to expand on what they were telling the researcher. This enabled participants to provide additional and/or more in-depth data that the researcher could then compare and contrast with previous data, with the aim of saturating codes and/or categories. In this respect, while interview data is constructivist in nature, the interview process is researcher driven. Interviews with health experts followed the same semi-structured format as those conducted with consumers.

Participants' diary entries

The use of participant diaries varies with the purpose of the research study (A. Richardson, 1994). The purpose of consumer diary entries, as a data collection method in this study, was to provide a mechanism for capturing participants' perspectives of their experiences without researcher input. Unlike interviews, which are researcher driven and rely on participants' recall and memory of events, diary entries capture participants' perspectives of their experiences at a point in time that is temporally close to when interactions occurred.

During the informed consent process, consumers were asked if they would like to keep a diary of their experiences of interacting with health experts. There were no prescriptive boundaries around time frames for keeping a diary or of diary formats. Of the five consumer participants who consented to keeping a diary, three provided data. This resulted in twenty diary entries. Apart from two diary entries, which were written within two days of participants interacting with health experts, consumers wrote their diary entries on the same day that interactions with health experts occurred. Entries were all in the form of emails to the researcher. Emails were transposed into word documents and coded and comparatively analysed with data collected and generated via other techniques.

Digital storytelling

Image making spans the evolution of humankind, from ancient cave drawings, artistic paintings, cartoons, photographs and film. Images are part of our everyday lives. We use images to tell stories, to record memories and to communicate. The introduction and development of digital media enables new ways of telling and sharing stories (Christiansen, 2011). Digital storytelling combines images and traditional oral storytelling, often with the addition of music, using digital technology. The researcher included digital storytelling as a data collection method to broaden the scope of participants to include people who are creatively and artistically inclined. Including digital storytelling as a data generation technique enabled participants to express themselves in ways other than spoken or written words (Banks, 2007).

Participants were recruited via print media to attend a two-day digital storytelling workshop. This resulted in a total of seven consumer participants. The workshop was held over two consecutive days and was facilitated by a research academic with seven years experience in facilitating health focused digital storytelling workshops. Digital stories were created using the software program iMovie on iPads. Although some of the participants were familiar with using the hardware, no participants had used iPads to make a short movie and none of the participants had used iMovie.

The aim of the two-day digital storytelling workshop was for participants to create a short three to four minute digital story around the category of ‘teaching health experts’. In the process of grounded theory research, data is comparatively analysed and where there are gaps in the developing theory, theoretical sampling of participants and theoretical saturation of themes are pursued with the aim of collecting or generating data to fill those gaps. Early rounds of generation, collection and analysis of data from interviews and participants’ diaries identified ‘teaching health experts’ as a category. The researcher anticipated that data from digital stories would provide additional data to further develop and/or saturate the category.

To enable participants to create their digital story, they were taught how to use iMovie on an iPad for the express purpose of making a digital story. On day one of the workshop, the facilitator led discussions and provided guidance about story construction, including an explanation of the elements of a ‘good’ story. Participants were prompted to think about a personal story that they would like to tell. Participants were shown how to use an iPad and asked to draft their story using the Notes application on the iPad or using pen and paper. At the end of day one, participants were asked to think about images, music and sounds that they would like to use to tell their story. Most participants took an iPad home and recorded sounds, took new photos or took photos of pre-existing photos to use in their digital story. Over the course of the workshop, the facilitator spent time with individual participants to ensure that they were comfortable with the process and with the story they wanted to tell. On day two of the workshop, participants were shown how to use iMovie on an iPad to bring the narrative, audio and image elements together to create their digital story.

Data from the workshop included demographic information questionnaires, researcher fieldnotes and six digital stories. All digital storytelling workshop participants completed a demographic questionnaire. The researcher attended the workshop as a non-participant observer and took twelve A4 pages of fieldnotes, which reflected discussions between participants, between participants and the facilitator and the researcher’s observations and reflections of the workshop and the developing digital stories. Of the seven workshop participants, six created digital stories. The remaining participant chose not to attend day two of the workshop, however they provided the researcher with their written story. The written story was electronically transcribed by the researcher and comparatively analysed with other data. At the end of the workshop, five of the remaining six participants were given a DVD copy of their digital story and the researcher also received a copy of each story. The sixth participant chose to upload their story to Vimeo® and provided the researcher, all workshop participants and the facilitator with the required password so that they could access the story online. Although the theme of the digital story telling workshop was participants’ experiences of ‘teaching health experts’ none of the resultant digital stories related to examples of when, how or what participants had ‘taught’ their health care professionals. Rather, stories predominantly related more broadly to the topic of this study; interactions between consumers and health experts.

Analysis of the digital stories was challenging. The researcher was initially inclined to analyse them from a visual research methodology perspective (Pink, 2007) and as stand-alone artefacts that had no connection to data previously generated by other methods. Through internal dialogues, discussions with the principal study supervisor, revisiting the grounded theory literature and acknowledging Glaser's (2004) mantra that 'all is data', the researcher was able to move beyond her initial inclinations and comparatively analyse digital stories with already established codes and categories.

Observation

Observation is traditionally a defining feature of ethnography (Hammersley & Atkinson, 2007). Outside of the ethnographic context, observation is used more variably and often in conjunction with other data collection and generation techniques. The use of observation in this study is congruent with the symbolic interactionist underpinnings of evolved grounded theory, which emphasise action, interaction and process. The researcher used "*non-participant observation*" (Gobo, 2011, p. 17, italics in original) which involves observing participants "without interacting with them" (Gobo, 2011, p. 17). The researcher chose this technique as it enabled her to observe, first hand, processes of action and interaction between consumers and experts. Observations provided the researcher with insight into interactions, processes and behaviours beyond participants' verbal accounts of their experiences of interactions with consumers and experts (Gobo, 2011; McNaughton Nicholls, Mills, & Kotecha, 2014). The researcher generated fieldnotes during and directly after observation sessions. Fieldnotes provided data, which was comparatively analysed against previous data to advance the developing grounded theory.

The researcher conducted approximately seven hours of observations in hospital, general practice and community settings. Observations in a hospital setting included observing four nurse participants and one Aboriginal Health Worker interacting with consumers in one ward at the public hospital. This resulted in 18 A4 pages of fieldnotes. Observations in the general practice setting were limited to observing a half-hour consultation between a consumer and his general practitioner. In the community setting, the researcher observed a study participant interacting with his support worker during physical exercise activities at the public swimming pool. Additionally, during the data collection and generation stages of the study, the researcher accompanied her husband to the hospital emergency department on two occasions and visited him in hospital during his four-day stay. Although these unplanned observations were not within the study's ethics approval protocol, the researcher was unable to 'unsee' what she had observed. The personal nature of these observations raised the researcher's theoretical sensitivity to the study data and the developing grounded theory.

Fieldnotes

Fieldnotes are a contemporaneous description of the researcher's observation of events (Birks, 2012; Montgomery & Bailey, 2007). Fieldnotes differ from memos in so far as they are made in the field. They record observations; whereas memos record the researcher's analytical thoughts about the developing grounded theory (Corbin & Strauss, 2008). Schatzman and Strauss (1973) suggest categorising fieldnotes as either ""Observational Notes" (ON), "Theoretical Notes" (TN) or "Methodological Notes" (MN)" (p. 99). Observational notes are a record of what the researcher saw and heard. They may contain participant's verbatim words, phrases or sentences but not include the researcher's interpretation of the event. Theoretical notes represent the researcher's thoughts about meaning making from the ONs. Methodological notes reflect the researcher's instructions and reminders to themself and/or a critique of the researcher's own acts and the methodological process (Schatzman & Strauss, 1973).

During this study, the researcher took fieldnotes during observation sessions in hospital, general practice and community settings. Additionally, the researcher took fieldnotes during the two-day digital storytelling workshop. Observation sessions resulted in 18 A4 pages of fieldnotes. Prior to conducting observation sessions, the researcher was not familiar with Schatzman and Strauss' (1973) categorisation of fieldnotes. While the researcher's fieldnotes were predominantly observational notes, the researcher concurs that it is "almost impossible to be purely descriptive when writing about incidents" (Corbin & Strauss, 2008, p. 123). The researchers observational fieldnotes contained elements of both theoretical and methodological notes.

Constant comparative analysis

Constant comparative analysis is a grounded theory method used throughout the grounded theory process from the moment data analysis commences until a grounded theory is fully integrated. The method involves constantly comparing incidents within the data to other incidents, incidents to codes, codes to codes, codes to categories and categories to categories (Birks & Mills, 2011). The grounded theory research process is by no means lineal. Coding data, constantly comparing data, analysing data and writing memos are iterative processes.

Through initial coding the researcher ascribed meaning to the data. Through the process of constant comparative analysis and through inductive and abductive thinking, the researcher developed intermediate codes, categories and sub-categories and selected a core category, which ascribed new abstract meanings to the data. The categories, sub-categories and the core category are presented in Figure 11. Use of the essential grounded theory methods of initial coding, intermediate coding and selecting a core category are explained in more detail below. As previously mentioned, these methods are used iteratively.

Core category

Outsiders in the experts' world

Category	**Sub-category**
Unexpected entrance	Emotional fluctuations
	Changing perceptions of self
Learning a new role	Acquiring knowledge
	Learning the language of health care
	Confronting mortality
	Cultivating support
Establishing a presence	Gaining confidence
	Choosing a voice
	Establishing relationships
Confronting the dichotomy of 'us and them'	
Tailored care	Listening and acting
	Accessing experts

Figure 11: Categories of the grounded theory *Outsiders in the experts' world*

Initial coding

Initial coding (Birks & Mills, 2011), or open coding (Corbin & Strauss, 2008), is the initial process of data analysis. During this process the researcher defined and labelled sections of raw data. Initial coding of data resulted in approximately 310 separate codes. Figure 12 provides an example of the initial coding process, using an excerpt from a consumer’s diary entry. The consumer emailed the diary entry to the researcher, who then copied it into a Microsoft® word document and coded it. Initial coding of interview transcripts and transcribed excerpts from audio recordings from interviews with experts, followed similar processes. The Table of Codes at the beginning of documents (Figure 12) provided an index of all codes and associated page numbers in documents, which enabled ease of access back to raw data. Initial codes were then copied from Microsoft® word documents into an excel spreadsheet and intermediate codes developed through processes of constant comparative analysis (Figure 13).

Table of Codes	**Page**
Assuming responsibility A55r4	1
Carers being excluded in the aged care sector A55r1	1
Carers wanting to be involved in care management A55r3	1
Changing processes of interaction A55r1	1
Treating dementia as an end point A55r5	2
Us & them in the aged care sector A55r2	1

1.	Changing processes of interaction A55r1 Carers being excluded in the aged care sector A55r1	I've just had a break through with mum at the home. A phone call re change in medication plan and blood tests being ordered. This is major for the culture is that once clients move in, the carer does not have a say
2.	Us & them in the aged care sector A55r2	and are definitely discouraged from asking why, and its a us and them battle.
3.	Carers wanting to be involved in care management A55r3	My next attempt is to be involved with case management meetings. I'm told this is possible just got to ask the person with 30 years experience in aged care if this is correct again.
4.	Assuming responsibility A55r4	My take on this is my mother charged me with the responsibility of her care. Mum’s health directive was "you know what i want, you know what to do". I have been there before as you know but the dr and staff don't.
5.	Treating dementia as an end point A55r5	Mum had chest pain, history of angina and a stent implant. The catch cry is they have dementia so just keep them comfortable, no specialist would do anything.

Figure 12: Sample initial coding document

Intermediate coding

Intermediate coding is the next stage of data analysis. During this stage the researcher connected initial codes together into higher-level codes. Figure 13 provides an example of initial codes advancing to intermediate codes. The initial and intermediate coding phases are iterative processes. The process of intermediate coding resulted in approximately 14 categories.

Source ID	Raw text data that inspired the Code	Initial coding	Intermediate	Category	Category	Subcategory
A26r74	*Like, before, you were sort of like - when you're up and able and running around at work and all that, you sort of look to the future thinking, 'Oh, I have three boys myself, three kids, and you know, I've always looked at when they have kids, you know, I'll be running around with them, I'll be the grandad doing this and that with them.' But as soon as the accident - when I had the accident, it's just changed my life again. Like, I don't look to that future anymore. I don't look to running around with the grandkids any more.*	changing life's focus	unexpected entrance	unexpected entrance		
A24r34	*Really upset, because as much as I wanted a diagnosis, I didn't want to be told that my spine was fusing together, and that there was no way that it could be fixed. So, I got put on chemotherapy drugs, which is one way that they attempt to deal with it, and that was horrible.*	unexpected entrance	Unexpected entrance	Unexpected entrance		
A55r1	*once clients move in, the carer does not have a say*	carers being excluded in the aged care sector	not sharing information	dichotomy of us and them		
A26r44	*Well, I've had a couple of nurses sort of mention it to me; say, "Find out what your blood type is, because there's certain things that is good for you and certain things that aren't, and you can overdo it on certain things and you can put on weight without realising it, and it could be just from a certain type of food." So I sort of looked into it a bit more,*	being guided by nurses' advice	nurses providing information	becoming a health consumer	learning a new role	acquiring knowledge

Figure 13: Excerpt of data analysis spread sheet

After completing intermediate coding of data, the researcher conducted iterative rounds of constant comparative analysis using manual data management techniques. This involved the researcher printing out the excel spreadsheets with the initial and intermediate codes. Data excerpts and their respective codes were then cut out and grouped into higher-level categories. Figure 14 provides a visual snapshot of this process in action. The pink labels in the photo on the right represent initial categories. The iterative constant comparative analysis process led the researcher to change and refine categories, to return to the raw data, to theoretically sample more participants and to refine topics of discussion during interviews for the purposes of saturating categories. Through these processes the grounded theory advanced until categories and sub-categories were fully developed.

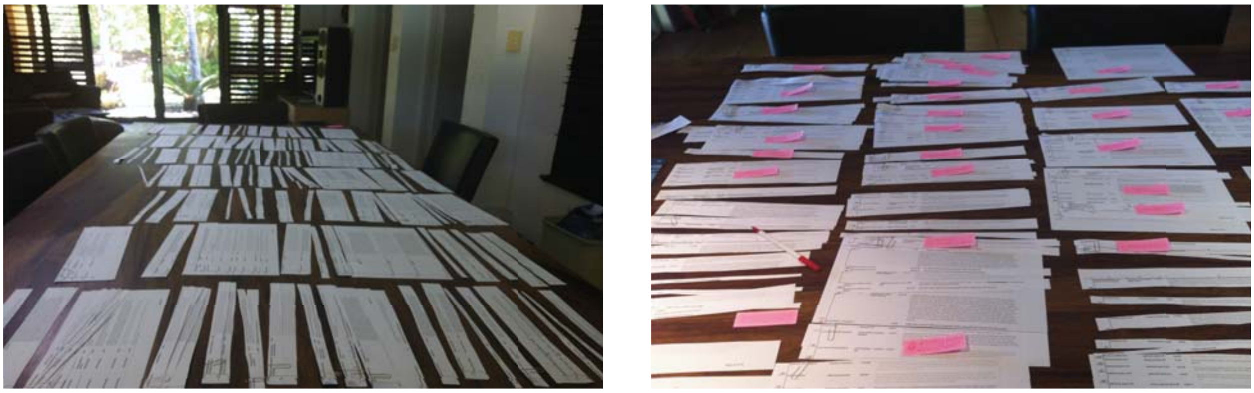


Figure 14: Visual record of manual analysis of codes into higher level categories

Select a core category

The importance of selecting a core category in a grounded theory study cannot be underestimated. A core category brings the elements of a theory together into an overarching category that encapsulates and explains a theory as a whole (Birks & Mills, 2011; Corbin & Strauss, 2008; Glaser, 1978). Glaser (1978) advises that it is “ok” to identify a core category, “which is a poor fit” (p. 94) until the researcher identifies one that has more explanatory power. Although not consciously following Glaser’s advice, the researcher identified an early core category, ‘Becoming and being a consumer with a life limiting condition’. After further theoretical sampling and continuing the process of constant comparative analysis of data, the researcher identified ‘Outsiders in the experts’ world’ as a potential core category during one of her regular weekly supervisory meetings. The researcher was explaining the ‘story’ of the data to her principal supervisor. The researcher had already identified three of the categories included in the final grounded theory and the concept of consumers being outsiders in the insider world of experts seemed to encapsulate the story and the variations within the story of each of the three categories. It was not, however, until the five categories within the grounded theory were identified and saturated that the explanatory power of the core category was fully realised.

To assess the explanatory power of the core category the researcher referred to Glaser's (1978) suggested criteria for judging a core category. Glaser (1978) does not suggest that the criteria should be applied prescriptively but presents them as a useful tool. Using the criteria as a guide, the researcher judged that the core category *Outsiders in the experts' world* clearly and meaningfully connected the five categories in the grounded theory; conceptually 'appeared' frequently in the data; was relevant and explanatory; and explained the consequence of being a consumer interacting with professionals in the social world of health care.

Theoretical integration

To theoretically integrate the grounded theory, the researcher drew from her bank of analytical memos to support processes of theoretical saturation of categories and identification of a core category and used 'storyline' as a tool to connect and explain the core category and the categories and sub-categories it encapsulates.

Storyline

Storyline is the process of writing the story of a grounded theory. "Grounded theories are in fact stories" (Birks & Mills, 2011, p. 118). The power of 'good' stories is in their ability to compel, to lead to reflection, to personally involve, to transform and to deepen the reader's ability to make interpretive sense of the central theme of the story (Van Manen, 1989). Storylines are both a tool for integrating a grounded theory and a means of presenting the findings (Birks & Mills, 2011).

The researcher began writing the storyline of the grounded theory not long after completing four rounds of data collection and generation with consumers. During the process of writing the storyline, the researcher put aside the findings and abstractly and creatively wrote the story of the interaction between consumers and experts based on categories and concepts developed during early data analysis. Writing the storyline enabled the researcher to identify gaps in the developing theory and to clarify categories and concepts. To address the gaps the researcher iteratively returned to the data and to the field and refined the storyline. Once the storyline was developed raw data was incorporated to support the story in much the same way as dialogue is included in a storybook or a novel.

Chapter summary

This chapter provided details of ethics approval including data storage processes. Sampling processes are described and details of demographic information obtained from questionnaires are provided in Figures 4 and 5. Concurrent data generation and collection methods of interviews, participants' diaries, digital storytelling, observation and fieldnotes are explained and Figure 7 provides an overview of the number of participants and quantity of data generated per data collection and generation technique. The chapter also provided an overview of data management techniques including explanations of the use of essential grounded theory methods of initial coding, intermediate coding and selecting a core category. The chapter concludes with a description of constant comparative analysis and theoretical integration processes. The following chapter presents the study findings.

CHAPTER 5: FINDINGS

> *All the world's a stage, and all the men and women merely players: they have their exits and their entrances; and one man in his time plays many parts.*
>
> *Shakespeare, As You Like It, Act II Scene VII*

> *All the world is not, of course, a stage, but the crucial ways in which it isn't are not easy to specify.*
>
> *(Goffman, 1959, p. 72)*

The social world of health care is the environment in which consumers and experts interact. The world of health care is governed by rules, regulations and codes of professional practice, which dictate where and how interactions take place. Interactions take place most commonly in hospitals, general practice and medical specialists' consulting rooms. Sometimes they occur in community facilities or consumers' own homes. Interactions commonly occur face-to-face or via telephone. As the use of electronic forms of communication increases interactions may also be conducted via email, video conferencing or other forms of social media.

Consumers and experts each assume different roles within the world of health care. Unlike the experts, consumers do not have a position description; their role is unclear to them when they involuntarily arrive in the health care system. Although it may be argued that consumer rights charters and principles provide consumers with some indication as to their role, the focus of consumer rights is on what consumers can expect from experts and health systems more so than on what experts and health systems expect from consumers. Consumers enter the social world of health care unprepared for their roles, whereas experts are educated and qualified to assume established roles. Consumers are outsiders in a world dominated by experts who understand the machinations of the social world of health care.

Being an outsider in a social situation is an experience that most people can relate to. A banker entering the world of law is an outsider in that world, as is a rugby player entering the world of basketball. When individuals enter ‘new’ social worlds they do not necessarily know the ‘rules’ of the unfamiliar world; the etiquette, behaviour, communication styles and technical terminology may be different from their familiar social worlds. New consumers entering the social world of health care are outsiders who are interacting with experts who are familiar with the rules. Familiarising themselves with the world of health care means that consumers must learn their new role and establish their presence. Consumers are often battling the dichotomy of ‘us and them’ in an effort to receive tailored care. Regardless of efforts to assume their role, consumers remain outsiders in the social world of health care. ‘Insider’ status is reserved for those who have the required expert knowledge and credentials. As one participant commented, ‘*You’ve got very highly trained professionals and us people who are ignorant of all that they know*’ (A75).

In the social world of health care, experts assume their professional identities when interacting with consumers. Professional identities differ from experts’ personal identities. During their education, experts are taught to establish and separate professional and personal identities. As one nurse explained:

> *You’ve got to protect yourself as a professional and even as a person outside in the community. Professionally you’ve got a code of ethics and professional conduct that you must maintain. It’s for your safety and the patient’s safety as well. You don’t want to start having dual relationships where you’re that person’s nurse but you’re also maybe their friend or colleague outside of work […] it starts to become a bit too personal in that sense. [...] Even if it’s someone that you know on the ward you try not to look after them as their nurse. Because of the blurring of the personal and professional boundaries. (A59)*

In their roles, experts use different strategies to maintain and protect their personal identity. The study participant cited above explained the strategy that she uses; ‘*When I go home I take off the professional nurse role. That gets put aside and now I am that person outside in the community*’ (A59). A general practitioner participant explained that living in a suburb, other than the one in which she works, makes it easier to maintain boundaries between her personal and professional identities.

The grounded theory *Outsiders in the expert's world* consists of five categories and their sub-categories, which represent a process experienced by people who unexpectedly enter the social world of health care and become health consumers. Consumers generally move sequentially through the stages of the process, although the stages may overlap or be revisited. The categories and sub-categories of the grounded theory are: 1) Unexpected entrance (Emotional fluctuations; Changing perceptions of self); 2) Learning a new role (Acquiring knowledge; Learning the language of health care; Confronting mortality; and Cultivating support); 3) Establishing a presence (Gaining confidence; Choosing a voice; and Establishing relationships; 4) Confronting the dichotomy of 'us and them'; 5) Tailored care (Listening and acting; and Accessing experts).

Unexpected entrance

After illness or injury strikes, a person makes an unexpected entrance into the social world of health care and in doing so becomes a consumer of new and different services. Illness can be either a diagnosed condition, or a range of persistent symptoms that defy diagnosis but affect a consumer's health and wellbeing. Becoming a health care consumer can also be experienced vicariously by those who are responsible for providing care to someone else experiencing illness or injury. Unexpected entrances are fraught with emotional fluctuations and changing perceptions of self that mark the beginning of '*another chapter*' (A26r12) in a person's life.

Emotional fluctuations

Unexpected entrances into the social world of health care cause emotional fluctuations that exceed everyday emotional experiences. Consumers described '*being very shocked and upset and sad*' (A46r208) and fearful and anxious of the unknown. Before entering the social world of health care, people cannot imagine what it is like to wake up in hospital '*with a tube hanging out of [their] throat, looking at a ceiling and this nurse leaning over just saying,* *“Relax” […] It is very scary to wake up like that, not moving, not knowing what’s going on*’ (A26_r7).

The following consumer found himself being taken to hospital by ambulance, after experiencing chest pains at home in the middle of the night; he had not seen the inside of a hospital for 30 years.

> *I didn’t know what to expect and all the rest of it. You know what I mean. If you go there because you cut yourself open and you need stitches, then you know what’s going to happen. (A13r42)*

Four hours later this same participant was diagnosed with leukaemia. His feelings of disbelief are emphasised in his retelling of the event. *‘I said to the doctor “it must be wrong, you’ve made a mistake with somebody’s blood, it’s not mine”. I said, “I’m a regular blood donor, I just gave blood six weeks ago. Surely it would have been picked up then”* (A13r46).

Consumers with persistent but undiagnosed symptoms experience similar emotional fluctuations to consumers who have been diagnosed. Additionally, they also feel frustrated, isolated and impatient; frustrated because they do not have a label to attach to their symptoms and isolated because they do not receive the support and understanding from others that a diagnosis often attracts. Wanting and waiting for a diagnosis is a test of patience, yet consumers fear what a diagnosis may mean. A diagnosis can answer consumers’, ‘*question of why I was feeling a certain way*’ (A46r363) and provide some ‘*relief*’ (A46r363). A diagnosis can also make consumers feel ‘*really upset. Because as much as [they want] a diagnosis*’ (A24r34) the reality can be worse than they had imagined. For one consumer, being ‘*told that [her] spine was fusing together and that there was no way that it could be fixed*’ (A24r34) was not what she wanted to hear.

A diagnosis or a prognosis, however, can also evoke motivation and determination as the following participant quote demonstrates:

> *I had about eight specialists around me of all sorts of degrees, saying, "You’re not going to walk again, you're not going to do this, and you’re not going to do that." Me, lying there, can’t move or nothing, couldn’t even move my head an inch side to side, laughing at them.*

> *They're like, "It’s no laughing matter." I said, "I’m going to move again. I’m going to get up, I’m going to stand up, I’m going to walk again." They're like, "You're too injured," and I’m like, no. From looking back then, it sort of drove me, because they said, no, I can’t do it. Some people sort of take it - they go backwards and give up. But that gave me the drive - I’m going to prove them wrong, I’m going to get up and I’m going to do it again. (A26r288)*

Changing perceptions of self

After the initial emotional fluctuations of an unexpected entrance peoples’ perceptions of self, change. Perceptions of both the internal self and the physical self, are intertwined with how consumers perceive themselves, how others perceive them and how they think others perceive them. Perceptions influence interactions between consumers and self and consumers and experts. Learning to reconnect with self and to trust one’s self again after being in hospital for an extended period of time is a challenge for consumers. In hospital *‘if anything goes wrong, everybody is here’* (A13r311). One consumer related the experience of returning home after nine weeks in hospital. His wife was at work all day, so he was home alone.

> *All of a sudden I was at home alone. It made no sense, because I was well or reasonably well, and I could look after myself. I could make myself tea and coffee and have lunch and all the rest of it. But it was just the fact that there was nobody here, when you're used to having, you know, all the ward staff there at your call. (A13r312)*

The consumer’s recount of his internal dialogue provides insight into his attempts to bring some perspective to the situation. I told myself, *‘stop being a bloody idiot and get on with it. What are you concerned about? You’re well’* (A13r314).

The changed physical self of another consumer, who is in a wheelchair as a result of an accident, has *‘made him open his eyes’* (A26r60) and think about his body in new ways. The consumer explained:

> *When the accident first happened I was – you know, I couldn’t take it [but] you’ve got to deal with it – you know, got to keep going. That’s my legs. That’s part of me now. (A26r97)*

Without the sensory perception of his body from the stomach down, the consumer perceives his body in more objectives way since his accident. His diet and weigh have become priorities for maintaining health because *'you can't tell when your belly's full'* (A26r38) and weight gain can lead to health complications.

Sometimes there is a dichotomy between how consumers perceive themselves and how others see them. One participant related how an expert and another person told her respectively that she *'had a significant physical disformity (sic)'* [*…and*] '[I] *look funny and walk funny'* (A32r242). The consumer had never perceived that her physical condition was *'that bad'* and added:

> *I never really get to see it myself. I can't turn my head far enough to see myself from the side anyway […] I didn't realise that I looked funny or walked funny, but I can't focus on it. I just have to deal with what I've got. (A32r244)*

Sometimes consumers' outward physical appearance belies their internal condition, which influences the ways in which experts interact with them. Consumers recounted occasions when their outward healthy appearance has meant that experts have not taken them seriously. One consumer related the following story:

> *I'd been home and had chest pains again. I was taking the painkillers, but it wasn't helping so I went to the [regional hospital]. I'd been there before and they were really great, but this time they were all different people.*
>
> *The nurse came up and he said, "What's the matter?"*
>
> *I said, "I've had chest pain all day, and I just can't get it under control."*
>
> *You know, the moment you're my age and you say chest pain, it starts the chain of events. So, they took me into the - you know, the bed they use for cardiac patients, and one of the nurses was putting all the pads on and everything, and sticking the leads on when the doctor came in. She came flouncing in […]. Without ever looking at me, she*

> *walks in to the staff and says, "What have we got going on here today?"*
>
> *So, one of the - the nurse that was doing the leads said, "We've got a middle-aged gentleman with chest pain."*
>
> *She turns around and she looks at me and says, "There's no chest pain with him, you're going to be out of here like that," and she snaps her fingers.*
>
> *Just as she snapped her fingers, the lady putting the leads on flipped the switch, because they're all on. The instant that she touched the switch, the alarm went off. So, then she [the doctor] came straight over like a magnet and says, "Do you have pain?"*
>
> *I was like, that might have been the first thing that you could say. Then she proceeded to be, you know, the best physician that you could ask for. So, and she actually - she knew the condition, and a whole lot. But all these things she should have asked right up front, and not, "You're going to be out of here in two minutes." (A27r118-121)*

Similarly, during interview another consumer commented on her attempts to make herself feel better: *'you're already feeling lousy and then you look lousy. I thought I have to reverse that, so I have to present myself nicely'* (A22r521). The consumer added that she believed her attempts to maintain an outward 'groomed' and 'presentable' appearance meant that experts were less inclined to believe she was sick.

During open discussions between consumers participating in the digital story telling workshop, a consumer told his story of being in hospital with sciatica. He had taken a shower to *'feel clean, feel better [and maintain] some dignity'* (A56) prior to the doctor's ward rounds. When the doctor arrived he made no attempt to enquire about the consumer's condition, but based on the consumer's appearance remarked, *'He's fine. He's had a shower. He can go home'* (A56).

In digital stories, participants represent and refer to self through the use of words and images. In one digital story, about caring for a family member, the consumer's story reveals her many ‘selves’: carer, sister, niece, granddaughter, member of a family unit and health professional (A52). In digital stories, consumers include images of self, which in most cases are distorted. These images are sometimes accompanied by words that suggest consumer perceptions of a distorted sense of self within the consumer-expert relationships. Figure 15 presents an image included in a digital story. The image is accompanied by the words, *‘we are you, you are we’* (A17). The image and the consumer’s spoken words suggest that, although the consumer feels invisible and powerless within the consumer-expert relationship, consumers and experts are not really that dissimilar in the face of illness.

Figure 15: Perceptions of self. Image from digital story - "Invisible" (A53)

Sometimes experts are forced to take on the role of consumer. In this situation they are both advantaged and disadvantaged; they ‘*know the way to navigate the system*’ (A60) but they are not treated ‘*like a normal patient*’ (A60). Being treated like a ‘normal patient’ is important to experts who find themselves in the hospital bed instead of beside it. When possible, experts will often conceal their professional self because they *‘don’t want [experts] to treat [them] like a colleague when [they are] actually just their patient’* (A27r177). Consumers conceal their ‘expert self’ by limiting the way in which they speak about themselves to experts and by avoiding the use of medical terminology. Being an expert advantageously provides these consumers with insight into what it means to be a consumer.

Learning a new role

The role of a health consumer is largely undefined. Consumers are not given a position description when they unexpectedly arrive in the world of health care. Similar to other undefined roles in life – parent, spouse, sibling – the consumer role is learnt and refined through experience. Consumers learn their role ‘on the job’. Learning the role means acquiring knowledge, learning the language of health care, confronting one’s own mortality and cultivating support.

Acquiring knowledge

Acquiring knowledge relates to consumers accessing and making sense of information, and living with and learning from their illness or condition. Consumers want to become informed about their illness or condition and their first step is accessing information. Being armed with and understanding information relevant to their health gives consumers a sense of control, leads to better-informed decision-making and gives them confidence to establish their presence within the world of health care. Consumers access information from a range of sources including experts, the Internet and from members of their social networks.

Interactions between consumers and experts provide an opportunity for experts to share their knowledge, provide consumers with information and direct them to sources of additional information about their health condition. For example one consumer participant recalled:

> *My GP explained it to me and she also printed me off – from a website – one of the government websites – the run down of it [health condition]. Then of course I’ve gone online and done a bit more research about it. Enough to give me a few questions that I need to ask her. (A46r357)*

Similarly, another consumer recollected how her pharmacist provided her with printed information about migraines, which she also used as a basis for accessing additional information via the Internet. The consumer then used her newfound knowledge of migraines and treatment options as a starting point for discussions with her general practitioner. Consumers seek information from experts about their condition so that they can better understand what it means for them. Before seeking information from experts, consumers consider which health expert would be best qualified to answer their questions when they seek information. One participant commented, ‘*the pharmacist is often better informed about drugs* *and sides affects and interactions and things like that than the doctor*' (A10r240). Equally, experts seek information from consumers to '*find out what [consumers] know*' (A58) and to build a rapport because, as one expert participant stated, '*if you haven't got a rapport […] I just don't think that you are going to get the best outcome for the patient*' (A58).

Although the Internet facilitates consumers' sharing their health experiences through mechanisms such as blogs, chat rooms and forums, none of the participants in this study referred to their use of these avenues for accessing information. Study participants use the Internet to search for general health information, treatment and medication options specific to their health condition, and ordering medication online. One consumer explained how a radio health report sparked her interest and she used the Internet to obtain additional information about medication she had been prescribed. '*I take glucosamine and I couldn't remember whether there is some research evidence. […] on the Radio National ABC Health Report there'd been something. So I looked that up'* (A10r186).

Sometimes consumers use information obtained from the Internet as a basis for treatment discussions with experts. One consumer participant, who was frustrated with her dealings with experts, used the Internet to '*become a doctor to herself* '(A24r224). She sourced information about her symptoms and presented her doctor with printed information sheets on a range of medications that she believed would be beneficial treatment options. The information sheets provided a discussion point and resulted in her doctor prescribing one of the medications.

Consumers do not always discuss their self-medicating practices with experts. Some consumers access information and purchase medication online without prior discussion with, or later advising, their health expert. The researcher obtained evidence of this type of scenario when observing interactions between a consumer and a cardiac patient educator during a pre-operation appointment. When questioned by the educator, the consumer revealed that he was taking medication that he had sourced and purchased via the Internet. The consumer mentioned that he had not thought to tell his doctor about the medication. Some consumers are more wary of using the Internet in health related matters, and approach with caution, recognising that '*there's no guarantee of quality on the Internet*' (A10r186).

Accessing and acting on information provided by family and friends can be detrimental to the way consumers manage their condition and/or can direct their interactions with experts. One consumer described how she *‘listened to a lot of people who were telling me that you create your own wellbeing’* (A32r37). This input from others influenced the way the consumer thought about her condition and convinced her that it was of her own making and that she *‘should fix it’* (A32r37) herself. The consumer stopped taking prescribed medication, spent a lot of money on alternative therapies and ‘*suffered greatly*’ (A32r37) before seeking advice from experts.

Friends were a great source of information for a consumer during his experience of having sciatica. This consumer was aware of the diagnosis and treatment processes as a result of conversations with friends who had experienced the same condition. In the consumer’s digital story titled, “Communication in just three words” (A51), he explains how he *‘knew the progression of treatment [for sciatica]: MRI, injection, operation’* (A51). The consumer used this knowledge to direct interactions with experts when he presented at the hospital emergency department. Accessing and understanding information enables consumers to be more pro-active in their interactions with experts when compared with consumers who have no prior knowledge of their condition.

Consumers acquire knowledge through their sense making of information and through the experience of living with a health condition. A study participant recounted how the experience of having a child with disabilities had influenced her interactions with experts. Prior to giving birth she would see a doctor ‘*tell them what the problem was, listen to what they’d say and go away and not really enter into a discussion*’ (A46r402). After years of interacting with experts, as both an individual consumer and as a parent, this same participant recounted that now she ‘*would question a little more [and] wouldn’t just take the doctor’s word*’ (A46r408). This participant attributed her increased assertiveness to a combination of knowledge gained over time, having a long-term relationship with her general practitioner and ‘*just growing older*’ (A46r406).

Learning the language of health care

Study participants do not consider learning the language of health care as an obstacle. They take a pragmatic approach to this task, as the following participant's comment demonstrates, '*something comes into your life and you have to deal with it. You can't give it away so you have to learn that language*' (A46r208). The language that must be learned includes general health terminology and language sub-sets that relate to specific health conditions, treatments and medications. Consumers must learn new words and their meanings to understand what is happening to them and around them.

Consumers will also assign their own meanings to previously-known words, and these meanings may change over time. For one study participant the word leukaemia meant, '*you're dead*' (A13r63) when he was diagnosed. His construction of meaning was based on what he had seen on television. Following initial discussions with his doctor the meaning of the word morphed into '*the fight of your life*' (A13r61). As he met and heard stories from other leukaemia patients, the word came to mean '*remission*' (A13r77) and possibilities.

Experts support consumers to learn the language of health care by putting terminology into language that consumers can understand. The impact of language choice and use cannot be underestimated and experts will adapt terminology depending on where a consumer is in their health care journey. This supports consumers to understand the language of health care and supports their adjustments to illness or injury. For example, as an expert participant explained, '*the words 'heart failure' are really negative words. It's a bad term. Even the heart failure team hate that term*' (A58). Instead experts speak to consumers in terms of '*your heart's not pumping as well as it could*' (A58).

Humour is part of language and a number of factors influence when, where, how and if humour is used in expert-consumer interactions. Factors include the relationship between consumers and experts, how consumers are feeling on a particular day and the point at which consumers are on the spectrum of their condition. For one study participant with a chronic life limiting condition, sharing humour with his general practitioner evolved over time and reflected the relationship that they had established:

> *we together have seen the lowest point, and I have no doubt that I still have his respect, even though he saw me at where I'd given up. So, that gave him license to share his personal opinion about my situation, which is far more helpful than his medical opinion. Then, from that - I mean, if you can do that, then humour comes easily, as soon as things start to improve. (A27r210)*

The situation was similar for another participant who has a long established relationship with her general practitioner. The participant recounted how during *'the first few years [she] wouldn't have said the kind of things that [she] says now'* to her general practitioner. She provided the following example, *'I've had a recurring UTI [urinary tract infection] for the last year, and it always happens after sex. We have a giggle about that. What's it worth? We have a giggle about that because we can be friendly like that'* (A46r288).

The following participant relayed a story about how nurses' use of humour provided his wife with a cue as to how he was doing:

> *My wife always said to me that she knew when I wasn't doing so well because the nurses treated me differently.*
>
> *I said "What do you mean?"*
>
> *She said, "Well when you were doing ok, they [the nurses] would come in and they would joke and they'd give you a ribbing about something or other. But when you weren't they were very much, "Would you like me to do this for you? Can I do this, can I get you that?" They treated you completely differently when you weren't doing so great." (A13r227)*

The early days of a diagnosis are not a time for humour but when consumers have accepted their illness they use humour more freely. An expert's comment highlights how using humour changes as consumers adapt to their diagnosis. A '*diagnosis [that] isn't a positive outcome diagnosis [is] not a joking matter […] once [consumers] have got used to their diagnosis they'll come in and have a joke with the staff*' (A58). One participant recalled a fellow consumer commenting to a medical receptionist, '*"Well, good news, I shouldn't be dead* *between now and next week when I see you"'* (A13r212). In a similar vein the same participant recounted a frequent exchange that he has with one of his specialist experts: '*Almost every time I see him, I walk in and he says, "So how are you?" and I say, "I'm not dead yet" and he says, "There's a bonus we weren't expecting"'* (A13r213).

Confronting mortality

When the role of being a consumer is associated with a life threatening or life limiting illness, consumers are confronted with their own mortality. Although family and friends support consumers in their illness, consumers are ultimately alone in accepting their own death. For some consumers, accepting the inevitability of dying is part of living, which makes '*the burden [of illness] easier to carry*' (A27r2). Religious faith supports consumers to confront illness and the possibility of dying from their illness. One consumer described the role of faith as follows:

> *This really struck me when I got sick – was that God says, "I will never ask you to endure more than you can handle." So, if you can handle this – and for real Christians, faithful Christians, it's a case of win-win. If you survive, you've won because you get to be here with your family. If you don't survive, you've won because you've gone to spend the rest of eternity with God. So, it really is a win-win." (A13r85)*

Consumers who accept their mortality are more likely to speak openly about death; not to mask their fear of death but to 'lighten' life. A general practitioner study participant recounted how a patient's acceptance and openness about illness and death guided frank discussions between them (A60). The same participant added that speaking openly about death removes the proverbial elephant in the room and alleviates the '*need for euphemisms'* (A60). Another expert commented that sometimes it takes consumers months to accept their diagnosis but even if they are reluctant to accept it '*eventually [their] bodies […] will tell them*' (A75).

Cultivating support

Cultivating support includes accepting unrequested support when it is offered and requesting support when it is needed. Family, friends, and social networks are sources of practical, financial and emotional support. Consumer participants recounted instances of receiving overwhelming support:

> *My friend from church has been mowing my lawn and trimming my edges and cutting my trees since [I got sick]. He has never accepted any payment for it. He has just - he just took it on himself that that's what he was going to do. Then, when both of us [the participant and his wife] were sick, you know, people would come over with home-cooked meals so that we didn't have to do it, and yes, there was just so much support. When we got into financial problems, they whipped the hat around at church and came up with literally thousands of dollars over the last four years to help us out. (A13r98)*

This same participant also told the following story:

> *We've got two whirlybirds on the roof, and they're as old as the house and the bearings started to make noises, so you couldn't sleep at night because, just all night, you'd hear this wowowowow. I rang a fellow at church who was in the building game, and I said, "Can you tell me where I can get these things, buy these things and get someone to fit it?" He said, "Leave it with me, I'll see what I can find out." I said, "Okay, thanks," and I went off to the hospital for a clinic appointment. When I came back from the hospital, I had two new whirlybirds on the roof. (A13r104)*

Knowing that there are people around who care or who are experiencing similar circumstances is just as important to consumers as practical and financial support. *“At church, everyone was very concerned and worried and wanting to help if they could help in any way […] We know we had the support from everybody […] a lot of concern and care, which is lovely”* (A3r222). Connecting with people in similar situations also supports consumers. A participant who has a child with disabilities explained how being in contact with other families in the same situation *“normalises the situation”* (A46r204).

Consumers who have physical disabilities, or who are parents of children with disabilities, often also require physical support. Learning to ask for and accepting support is non-negotiable for these consumers. One participant has full time support workers who assist him to shower, dress, clean and cook. The adage that ‘no man is an island’ comes to the fore; being a health consumer is not a journey that people choose nor is it a journey they choose to tread alone.

Random acts of kindness by strangers also support consumers in unexpected ways. A consumer, who is in a wheel chair as a result of an accident, told a story of a woman *‘who […] like an angel – just popped up and just disappeared like that’* (A26r412). The consumer was at the supermarket cash register with his groceries and when he went to pay his bankcard did not work:

> *I didn’t have any other cards, or I had other cards but I didn’t have any money in that, because I had to transfer money over. I said to the lad, I said,*
>
> *"Sorry, I can’t pay for it, I can’t take it." […]*
>
> *He was like, well, "What am I going to do with it?"*
>
> *I said, "Well, you’ll have to get somebody to put it back on the shelf." I was getting flustered and I was getting shamed, you know, because there were a lot of people lined up behind me, and I was right by the walkway where people come in and out. All I remember then was, this lady just leant over and said,*
>
> *"Sir, are you all right?"*
>
> *I said, "Yes - no, I’m fine."*
>
> *Then she goes, "I heard what's happening," and she looked at the lad and said, "How much is that?" The lad's told her how much, and she goes, "Here," and just paid for it.*
>
> *I said, "Can I get your name and number and, you know, I’ll fix you up, I’ll get the money, I’m good for it." I said, "Give me your name and number, and I’ll get back to you."*
>
> *"Oh, no, that's okay, that's fine." Paid for it, got her change, and then I turned around and said, "Thank you very much, you didn’t have to."*

> *She goes, "No, that's fine, I'm glad I helped you out," and I turned round to thank her again and she was gone. (A26r409-411)*

Consumers living with mental illness, or who are parents or carers of people living with mental illness, are often isolated in their journey prior to seeking professional support. For these consumers, seeking support from health professionals is often a 'cry for help', which is not always heard or does not meet their expectations. One consumer's cry for help at a hospital's Emergency Department resulted in her being admitted to hospital overnight. The following morning, instead of the consumer's condition being addressed, the doctor on ward rounds perfunctorily remarked, '*It's Sunday. There's no mental health staff today. Go home. See your own GP next week'* (A48r1).

A consumer who participated in the digital storytelling workshop titled her story *Invisible* (A53). The digital story speaks directly to health professionals and tells the story of her family's struggle of living with the *"nightmare"* of her son's mental illness. The story opens with images of family photos, an eerily haunting soundtrack and the participant's voice; "*Invisible. Do you see us? Do you hear us? Do you know us?"* (A53). Rather than meeting the family's cry for help, seeking professional support amplified the family's struggle. They felt even more isolated as they searched for health professionals *"with heart and soul"* (A53) to care for and understand their child. Establishing a presence is difficult for consumers with mental illness and for consumers who care for someone with mental illness as the stigma of mental illness clouds interactions between them and experts.

Establishing a presence

As consumers learn their role they establish their presence in the social world of health care. To establish their presence, consumers need to gain confidence and choose a 'voice'. Confident consumers assert their presence and provide feedback directly to experts. In choosing a voice, consumers make decisions about how they will interact with experts. The 'voice' that a consumer chooses may be the result of their increased confidence, the influence of their individual personality or it may reflect where they are on the spectrum of their illness or condition. Consumers establish relationships with experts over time. The most valued relationship between consumers and experts is the relationship between a consumer and their general practitioner.

Gaining confidence

It is challenging for consumers to gain confidence in their interactions with experts when experts exclude them from discussions. As one consumer’s comment highlights, there were *‘lots of people [experts] standing around talking to each other about me* (A50). Gaining confidence is also challenging for consumers when they perceive that their inclusion in discussions with experts is tokenistic. During the digital storytelling workshop, participants’ openly discussed their experiences of interacting with experts. During discussions, a consumer vented her frustration with experts caring for her son, who lives with mental illness. The consumer’s comment, which the researcher captured verbatim in fieldnotes, reflects the consumer’s perceptions of mental health experts as non-inclusive: *‘You see what you want to see, hear what you want to hear and know what you want to know’* (A56).

Consumers gain confidence over time by acquiring knowledge and through the lived experience of being a health consumer. A participant who had been a consumer for about four years at the time of interview had spent numerous extended periods in hospital. He recounted the following incident, which demonstrates the ways in which confident consumers can change the course of interactions with experts:

> *he [the registrar] would ask me a question and I would begin to answer, and only halfway through, he would talk over the top of me. I let him go, and he did that probably six or seven minutes. This was in the ward, yes. Like, there was him and - because there's usually a group of between three and five of them. Yes, there was him and two or three others, I forget how many. But he was doing all the talking. Eventually, I pulled it up and I said, "Listen, do you want to hear what I've got to say, or don't you?" I said, "Are you actually interested?" He said, "What do you mean?" I told him. I said, "You asked me a question, I start to talk, and then you talk over the top of me. Now, do you really want to know, or don't you?" I said, "Because if you're just*

> *going to talk over the top of me and not bother listening to what I've got to say anyway, then I don't want you treating me." So, and they were good after that. Actually, he was - he really changed his attitude after that. (A13r267)*

The same participant also used his confidence to provide positive feedback directly to an expert:

> *One particular fellow, when I heard that he was leaving to go to the Royal Brisbane Hospital, I said, "Don't stop being the person you are." I said, "You are very good at communicating to us [consumers] what is happening and what you're thinking about our condition," and I said, "Don't stop doing that, because that's what people want to know. They don't want to be left in the dark about their health." I said, "You're very good at communicating that. Keep it up." (A13r287)*

Another consumer participant attributes the long-term relationship she has with her general practitioner as a contributing factor to her level of confidence with other experts:

> *I think by having a long-term relationship with a doctor, I've definitely learnt. It's given me courage or the experience to be forthright with other medical people […] it's really taught me to be more confident. (A46r400)*

Choosing a voice

Consumers want to be heard and they have to find their voice and use it. Consumers use a range of 'voices' or approaches when interacting with experts, including a 'squeaky wheel gets more oil' approach, a warrior approach or a gentle, patient approach. A consumer, who is also the mother of a child with disabilities, commented during interview that she needs to *'speak loudly'* (A46r221) to be heard and referred to the adage *'a squeaky wheel gets more oil […as her] mantra'* (A46r222). This participant's experience with experts led her to the conclusion that as a consumer you have to *'say what you need, what you think you need [because] no one's going to come looking to help'* (A46r223). The participant explained that before coming to this realisation she would answer *'I'm fine'* (A46r264), if someone asked her how she was feeling. The participant elaborated further:

> *I've learnt that you can't underplay the medical things. If you underplay a medical issue, no-one's going to think it's important enough to do anything about it. It's a realisation, obviously. I've learnt that and I've applied it also when dealing with Disability Services - to get the respite you have to tell them about the worst parts. You don't ever say, "I'll be alright. That's only two days a week." You just tell them about the two days a week. It's like making sure that you verbalise your needs. (A46r264)*

Another participant, whose rare health condition had implications in the upcoming birth of her child, changed her tact after her initial contact with the hospital elicited a '*"No it's all right"*' (A32r167) response from experts. Using a 'squeaky wheel gets more oil' approach elicited, in the participant's words, an "*'Oh crap, we've got to get that sorted and figure out a plan'*" (A32r167) response from experts, and the consumer's needs were met. The same participant went on to explain that the extent to which one is 'heard' often depends on the person you are speaking to and the context of the interaction. For example, she perceives that there is a *'lack of communication'* (A32r171) in the hospital system as doctors there are busy, whereas in the general practice setting *'there's no having to push. […the doctor] listens to my concerns'* (A32r171).

Using the 'squeaky wheel' approach does not always produce desired results; external factors also influence outcomes. A consumer's digital story tells of their experience of arriving at a hospital emergency department with severe back pain. The consumer used a 'squeaky wheel' approach and repeatedly asked to have an ultrasound or an MRI so that the underlying cause of his pain could be ascertained and he could be given appropriate treatment. His requests were refused without explanation. Later, the participant overheard a conversation between the treating doctor and another staff member; there were no radiologists on-duty and hospital policy precluded one being called in on weekends due to financial costs. The consumer was sent home with medication and returned to the hospital via ambulance three days later; he then spent three nights in hospital.

Taking a ‘warrior’ approach is familiar to consumers who are carers. As carers for others, they ‘fight’ for those who cannot advocate for themselves. In a digital story titled *Invisible* (A53), a consumer included an image of two dinosaurs fighting (Figure 16) and the spoken words, *‘Then we came to you. Then we must become warriors’* (A53). The image and the consumer’s words, symbolise the constant battle that carers face when they interact with the health system and experts.

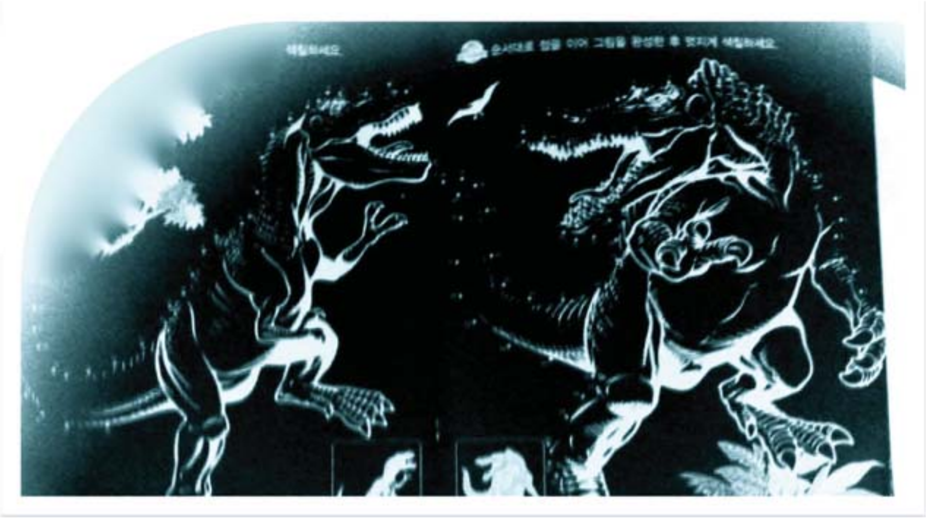


Figure 16: Fighting dinosaurs. Image from digital Story - "Invisible" (A53)

Interacting with carers is also a challenge for experts. An expert with 27 years experience commented, *‘if you’ve got two people in the room it changes the dynamics […] you’ve effectively got two patients’* (A60). This same expert further explained that, when interacting with consumers and their carers, her priority is *‘remaining engaged with the patient’* (A60). The strategies she uses include addressing the patient by their name, asking the patient if they understand what is being discussed and asking the patient if they are happy with the decisions being made in relation to their health care. In some situations *‘patients are not cognitively aware of what’s going on’* (A59) and carers truly become the voice for another.

Consumers with life threatening health conditions tend to choose a gentle, patient approach in their interactions with experts. During interviews and observation these consumers spoke with, and demonstrated, humility and patience in relation to their interactions with experts. One consumer explained:

> *Attitude is everything. I've seen people in there who really treated the staff with disdain, you know, because they wanted attention and they wanted it now. Whereas, I was always patient, knowing that there's more people in there than just me and some of them are in a worse condition than me. (A13r206)*

The same consumer further explained that when he witnessed other consumers behaving badly he felt *'Terrible. It made me want to climb out of the bed and go over and smack them'* (A13r210).

Establishing relationships

Relationships between consumers and experts are often established over long periods of time. Of all the relationships that consumers have with experts, their relationship with their general practitioner is the most intimate. Consumers spoke about the changes in their lives that their general practitioner had seen them through: relationship break-ups, depression, the lowest point in their illness and being close to death. Regardless of the experiences that consumers share with their experts, professional boundaries are maintained.

Professional codes of conduct and boundaries established by experts are generally respected and contain the relationship on a professional footing where the expert prevails. For example, one consumer participant commented that although her general practitioner *'knows her whole situation […] dealing with a marriage breakup, dealing with diagnoses of osteo-arthritis and problems with depression and seeing a psychologist'*, she respects her general practitioner's professional boundaries. *'I've bumped into her a couple of times* [outside of the general practice] *and I just say hello and I move on. It's not like – I don't stop to have a chat'* (A46r398).

Sometimes, experts will relax professional boundaries. For example they may make exceptions in the last stages of a consumer's life. In this situation general practitioners might give their personal telephone number to a consumer, but not before considering '*what [they] are willing to do for that person. Like go and visiting them at the drop of a hat*' (A60). General practitioners are not the only experts who are willing to blur professional boundaries. A consumer recounted how the specialist doctor, caring for her uncle, had given her all of his contact numbers and advised her that she could contact him 24/7 as needed.

Within doctors' surgeries, power differences between consumers and general practitioners or medical specialists are less pronounced than in the hospital setting. The consultation space in doctors' surgeries is generally limited to one-on-one interactions, except in instances where consumers are accompanied by a carer or family member. The duration of the professional relationship between a consumer and their doctor, influences the structure of their relationship. The longer a 'patient-doctor' relationship has been established, the more relaxed interactions are likely to be. In this scenario the consumer is in a position of greater power than the patient in the hospital bed, and is therefore more likely to establish their presence. In a doctor's surgery the consumer influences, to some degree, when an encounter will occur as they have usually initiated the appointment.

Consumers often arrive at their appointment with a mental list, or even a physical list, as the researcher noted during an observation session between one consumer and his general practitioner (A43). Being prepared for the appointment enabled the consumer to control how the encounter commenced. However, when the general practitioner asked the consumer to reflect on his condition and on his request for medication, the consumer's demeanour and body language changed; he sat less upright, was not as confident and appeared dejected. The extent to which consumers maintain control of the whole encounter depends on how the situation unfolds and how each actor responds to the other.

Confronting the dichotomy of 'us and them' (A55r2)

The social world of health care dichotomises consumers (us) and experts (them). In health care settings the dichotomy of 'us and them' is characterised spatially, physically and through the asymmetrical relationship between consumers and experts. The asymmetrical relationship is supported by social structural elements such as culture, systems and decision-making powers engendered by consumers' and experts' roles. Some consumers and experts confront the dichotomy of 'us and them' as they would a battlefield in which a victor must emerge. These actors do not transcend social structural elements but wield them as weapons. Other consumers and experts are willing to transcend structural dichotomies of ‘us and them’ to create and negotiate reciprocal interactions that meet each others’ needs and expectations.

Health care settings are spatially dichotomised into consumer spaces and experts’ spaces, although sometimes the two overlap. Consumers are generally spatially confined to hospital wards and hospital and medical practice waiting areas. Designated experts’ spaces include offices and hospital ward stations. Consulting rooms and operating theatres are designated spaces into which experts invite consumers to enter.

The physical positioning of experts during interactions with consumers often represents a reality of the division between the two groups. During observation sessions, the researcher observed experts standing above consumers who were laying or sitting in hospital beds. The asymmetrical positioning of consumers and experts in these scenes perpetuates a dichotomy of ‘us and them’. The researcher also observed consumers and experts interacting in scenes set in hospital and private practice consulting rooms. Although, in these scenes consumers and experts are physically positioned at eye-level, the expert’s desk and professional work-space are a physical cue of the dichotomy of ‘us and them’.

The researcher observed exceptions to the common scenes presented above. During observations in a hospital ward, the researcher observed interactions between an Indigenous Health Worker (IHW) and Indigenous consumers. In these scenes the IHW sat on consumers’ beds. By entering the consumer’s space and sitting at eye level, the IHW reduced the spatial and physical divide between herself and Indigenous consumers. In these scenes, consumers appeared more relaxed and comfortable than consumers observed in other scenes depicted above.

Consumers appreciate experts’ attempts to break down common spatial and physical barriers. A consumer, who has a child with disabilities, emotionally recounted the following scene, which she observed between a medical specialist and her son:

> *He [the doctor] made him sit on the bench so he could see him eye to eye, and explained everything. He wouldn’t even look at me, and I*

> *thought, this is great. He called him by name, and explained everything to him as a seven-year-old and he [my son] took it all in, you know. As a mother of a child with a disability, it just - it meant so much to me, you know, that someone would take the time. (A3r99)*

The asymmetrical relationship between consumers and experts is characterised by: imbalances in decision-making power between the two roles; the ways in which members of each group approach interactions; and the ways in which members of each group seek to transcend dichotomies. A participant who is the carer of her elderly mother living in an aged care facility described the culture within the facility as one where '*once clients move in, the carer does not have a say and [they] are definitely discouraged from asking why – it's an us and them battle*' (A55r2). In a digital story, another consumer related her discussion with an expert about treatment options. The discussion ended with the expert stating, *"If you don't want to get anymore needles done, there is nothing more I can do for you."* (A50)

Consumers who are parents of people with mental illness described similar scenarios of being excluded from decisions once their adult children entered the social world of health care. One consumer carer, who participated in the digital storytelling workshop, described her family as *'warriors […at] war'* with the system and experts (A53). The same participant emphasised dichotomies between consumers and experts, when she questioned the following in her digital story: *'Who is powerful, who is weak? Who is right, who is wrong?'* (A53).

Some consumers and experts approach dichotomies of 'us and them' with a willingness to negotiate decisions. A consumer participant who had reached a point in his treatment where he wanted to stop all his medication was met with resistance from experts. Negotiations between the two resulted in the consumer and experts finding a middle ground. In the following excerpt from an interview transcript the consumer relates his conversation with experts:

> *I just said, "Look, why don't we just stop all the medication?"*
>
> *And they said, "Well, you know, this could happen and that could happen."*

> *I said, "Yes, that could, but I really can't do this anymore."*
>
> *The haematologist said, "I can understand that." He said, "How about if we stop everything?" except my anti-rejection drugs and two prophylactic antibiotics that I was taking.*
>
> *I said, "Okay, well, that's a start." (A13r153)*

Confident consumers challenge the dichotomy of ‘us and them’ and, as a result experts are often willing to make changes, adapt and even ‘bend’ the rules to meet consumers’ needs. A participant whose elderly mother lives in an aged care facility had the confidence to persistently request involvement in her mother’s care and reported in a diary entry that she had ‘*had a breakthrough […] a phone call regarding change in [her mother’s] medication plan and blood tests’* (A55r1). In the same diary entry, this participant identified her next battle as: ‘*my next attempt is to be involved with case management meetings*’ (A55r3). The following consumer’s comments also highlight how confident consumers can challenge the dichotomy to generate change:

> *they [experts] would talk amongst themselves over by the door about what they were going to do, and then come back and say, you know, "Somebody will be around later on to give you a shot." I said, "No, hang on a minute, I'm here. I'm still awake. I'm still alive." You can tell me what's going on, and yes, they completely changed after I mentioned it to them, too. Because I said to them, I said, "Look, you know, not all patients want to stay completely ignorant of what's going on." I said, "A lot of us like to know what your thoughts are, what you think is wrong with us, and how you think you're going to fix it." (A13r275)*

Consumers also described how their general practitioners were sometimes willing to adapt and challenge the rules. One consumer takes medication that, under regulations, can only be prescribed one script at a time. The participant explained how he manages to negotiate with his doctor to have two prescriptions written at a time:

> *He [the general practitioner] starts out telling you the sort of party line of what can and can't be done, and then when I dig my heels in*

> *and say, "Well, I can't do it that way", he'll pick up the phone and phone Canberra and get permission [to issue two prescriptions at a time]. (A27r103)*

One month after the interview, in which the consumer related the above scenario, the researcher observed a similar situation unfold between this participant and his general practitioner.

Another consumer explained how he confronts structural dichotomies that dictate the relationship between him and his fulltime support workers. The support workers are employed by a private organisation under contractual arrangements that guide the scope and delivery of support worker services. The consumer explained that he is not rigid in following the contractual arrangements but seeks to negotiate arrangements that meet his and his support workers' needs. The consumer elaborated and explained how, for example, if on a particular day he wants a support worker to come in later than rostered, he is required to '*ring up the association and you've got to tell them why and how come. It's like twenty questions'* (A26r379). The participant went on to explain how, for him, the relationship with his support workers takes precedence over rules:

> *So, you know, if something comes up, something happens, we help out each other, because that's the only way to do it, you know. You get a better relationship that way. Better than, you know, straight down the middle with the rules - you know, you've got to stay on this line, you can't jump off it. You know, I'm not like that. We've got to work it out with each other, help each other; we've got to work together […] I'm sort of like a – probably not a rule breaker but you know I do bend them a bit. (A26r384)*

In some instances, participants are willing to defer to the expert's judgement, particularly doctors. A participant who has a young adult child with disabilities wanted to have her child's medication dosages decreased but '*as the doctor said, "Look, it's working, let's not play with it"*' (A3r78). An expert's comment during interview emphasises both consumers' and experts' deference to doctors' judgements: *'I don't think we are over our awe of doctors'*

(A75_17:49). The expert's tone of voice and the way in which she used the collective 'we' signified that doctors' judgements are upheld by both consumers and other health professionals.

Tailored care

Traditional definitions of tailoring care relate to experts developing individual consumer care plans. Findings from this study, however, illuminate tailoring care as more fundamental than care or treatment plans. Tailoring care to meet individual consumer's needs requires consumers and experts to listen to each other and to act, and access to experts that consumers know and trust. One consumer described the process of tailoring care as *'a consultative thing'* (A13r261).

Listening and acting

The participant cited above acknowledged that he always felt listened to *'because I would tell them [the experts] everything about how I felt. They would – they always seemed to act on what I said'* (A13r265). Other consumers referred to the process as follows:

> *He [the expert] listened. He gave sympathy. […] It's such a big difference. It's not just like prescribing – it's just talking you know, and thinking. Weighing the good and the bad of the medication. We discussed together. It's such a good feeling. (A22r431)*
>
> *All I said to the first doctor was that I have a lot of difficulty with everyone being around me when I don't have any control. I'd no sooner said it than sort of extraneous people were moved away. So, he heard every word that I said, and put the appropriate amount of action. (A27r36)*

Tailoring care to meet consumers' emotional needs is also important. A consumer, who has a chronic life threatening illness, recounted how he and his general practitioner have constructed a scenario that they will play out when the consumer reaches a point where he wants to *'give up'* (A27r105). Enacting the scenario will not alter the consumer's physical condition but will, to some extent, address the consumer's emotional needs:

> *We have a code now. So I told him, “Well, when I get to the point - to that stage again, I'll just tell you that I'm ready for a short trip to Switzerland”. He says, "Is there anything that I can do to help that I'm not doing?" I said, "Yes. When I come in and I look really bad, no matter what, I want you to tell me how well I'm doing. I promise you that I'm going to pretend that I believe you." (A27r107)*

When consumers feel that experts do not listen and therefore do not tailor their care, consumers needs are either not met or are not met in a timely manner. One consumer’s digital story includes an image of males in ‘slave gangs’ followed by an image of the Australian Indigenous flag (Figure 17). The images are accompanied by the consumer’s voice over that refers to experts *‘not listening because they don’t have to’* (A49). The symbolism of the images links the consumer’s cultural identity to concepts of oppression and exclusion, which are expressed in the consumer’s spoken words.

Figure 17: Identity. Images from digital story - "He is my son" (A49)

Consumers also revealed that sometimes experts hear and listen but do not act in a timely manner. During open discussions in the digital storytelling workshop, one consumer related to the group how experts on a hospital ward listened to him *‘crying, turning and screaming in pain’* (A56) without acting. During interview, another consumer related a similar story in which experts heard him but delayed their actions to meets his needs.

> *My bed was right behind their chairs - there was only glass between us. So, I asked them - I said, "Could you get my injection of Fentanyl ready?" and the one said, "Yes, no problem."*

> *I waited for 20 minutes, and they were right there, just chatting. So, I got up and went to the door and I said, "Did you forget?" She looked at me and she says, "Oh, I'm sorry, I'll do it right away," and then nothing happened. It started at 10 o'clock at night, and at 2:30 in the morning I still hadn't had the Fentanyl. (27r50)*

The process of tailoring care also requires consumers to listen to and to act on experts' advice. The previously cited consumer related a story of how he presented to the Emergency Department of a public hospital in a city other than where he lives and where his medical records are kept. The following interview excerpt provides an example of how by listening to and acting on an expert's advice, the consumer was able to receive tailored care in a hospital in another city.

> *The triage nurse was on the phone and the computer at the same time, and she said, "Just take a seat, I'll be with you in a few minutes."*
>
> *When I'd been discharged from Cairns Base [hospital], the doctor who did the discharge - I asked him if he had any advice, and he said, "No, not really, because you're on top of things." He finished doing all the paperwork, and he said, "Actually, there is something," because he had been there when I came into emergency. He said, "The next time you get sick, if you're not here when that happens, you need to emphatically tell them how unwell you are, because you never look it."*
>
> *So those words came back to me when I was in Melbourne, and so I didn't go and sit down. I just stood there for a few moments, and she [the triage nurse] was trying to get a bloody application to work on her computer, and that's what was more important than triage. So, I finally said to her, when she stopped talking to the IT person - I said, "I'm 57 years old, I've had chest pain for 16 hours, and my pulse is so erratic I can't count it." So she finally looked up and said, "Just a minute," and came rushing around and got a wheelchair. By the time my friend parked the car, you know, and got in, I was already in the resuscitation room and they had lines put in, and they already had defibrillated the first time by the time he came in. So, that's how*

> *serious it was. Like, my pulse was hitting 250. So - so now I know to tell people. (A27r116)*

Accessing experts

Consumers depend on experts to meet their health care needs. Access to experts when consumers need it and to experts that consumers know and trust contributes to consumers receiving tailored care. Prompt access to experts is often limited to consumers whose condition requires immediate attention or who are in the final stages of life.

> *Because of my condition, [the doctor is] very accessible. If I have any concerns at all, I can ring him. Usually, obviously, he's not the one that answers the phone, and I tell the nurse or the receptionist, whichever one answers the phone, who it is and that I need to talk to the doctor. They say, "I'll get onto him and he'll call you back," and he usually calls back within one to two hours at the most. (A13r16)*

Another consumer, who was caring for a family member who was in the final stages of life, explained in her digital story how *'the specialist had given me all of his contact numbers and I'm allowed to ring 24/7 if needed'* (A52).

Access to experts is not always so readily available for other consumers. During consumers' open discussions in the digital storytelling workshop two participants, who are both mothers of adult children with mental illness, explained how they were excluded from participating in any aspect of their childrens' care. It was unclear, from the conversation, what the mothers' legal status was in relation to accessing information or being involved in their childrens' care. Nonetheless, both mothers expressed concern for their children and were upset and angry that *'the system took them [their adult children] away'* (A56).

These consumers have no way of knowing if their children are receiving tailored care and they are excluded from contributing in any way to their child's care. One of the mothers described how she had asked for and needed help from experts when her son was admitted to the hospital psychiatric unit. '*Nobody ever phoned me, nobody ever returned my calls'* (A56). For this consumer, accessing an expert who had *'passion, professionalism [and] intelligence'* was important and akin to *'finding a friend'* (A56). The other mother explained that experts had told her, *'we can control our patients better without the family around'* (A56).

Accessing experts close to their home and in settings familiar to consumers, supports tailored care. Sometimes consumers have to travel from regional or remote areas to capital cities or larger regional hospitals to receive care. Being away from family and support networks is isolating. Consumers prefer the familiarity of smaller regional hospital facilities, which they believe foster more personalised care:

> *I can remember going into the ED one day and just walked through the door - and that's all I did, was just walk through the door - and the girl behind the counter said, "Hi [consumer's name], come on straight through." It made it all bearable, for a start. It made me confident that I wasn't just a number, I was being treated as a person. It made me glad that I was being treated in Cairns, and not in a capital city where possibly I may have been just a number. Yes, as I said earlier, it made a really bad situation feel a lot better. (A13r187)*

This was not an isolated occurrence. In a diary entry a few weeks after interview, the same consumer wrote about a similar instance:

> *The nurse that does the pre-clinic blood pressure and weight checks was chatty and efficient but still able to make me feel that I was a person rather than something on the assembly line. All of the oncology seem to have a gift for making us feel that we are their only patient, with the very personal care they give. (A25r3)*

Findings conclusion

Although Shakespeare states that we are merely players on a stage and that we each "play[…] many parts" (As You Like It, Act 2), the role of consumer is not a role that people choose to play. A diagnosis or recurrent symptoms engender a reality that thrusts people into the consumer role. The social world of health care is constructed of legislative frameworks within which people who willingly assume the role of experts provide care to those who unwillingly assume the role of health consumers.

Regardless of whether a consumer's unexpected entrance is the result of an accident, a diagnosis or being a carer of someone who has experienced either, consumers experience all stages of the grounded theory presented in this Findings chapter. Although consumers generally move sequentially through the stages of the grounded theory, the stages may overlap or be revisited. For example, a consumer who has received a diagnosis may experience each stage of the process only to find themself catapulted back to an earlier stage and assigned a new diagnosis. A new diagnosis has the effect of an unexpected re-entrance and may occur at any stage of the process. A consumer's previous experience gives them some familiarity with the process of being an outsider in the expert's world but it does not change their outsider status.

Key findings

1. People experience 'culture shock' when making unexpected entrances into the world of health care.
2. People are not prepared for their role as health consumer.
3. Being a health consumer takes time to learn and adapt to.
4. Consumers rely on experts in making decisions about their care.
5. Consumer involvement in decisions concerning their health care requires health literate consumers, flexible health professionals and flexible health systems.
6. Consumers' and experts' interactions with self and other are fundamental to the way in which consumers participate in their health.
7. Confronting the dichotomy of 'us and them' requires negotiation, reciprocity and respect for self and others.

Digital story

To provide the reader with an example of a digital story the researcher wrote a script using excerpts of data collected from and generated with study participants. The voice in the digital story is the researcher's, however all the words are those of the study participants. The researcher selected data excerpts that represent the categories of the grounded theory and tell the story of *Outsiders in the experts' world*. The digital story is accessible via the YouTube link: http://youtu.be/dGIGotvP9IA.

Chapter summary

This chapter presents the findings from this study. The findings are the researcher's interpretation of participants' stories, which were collected and generated told through a variety of means. The grounded theory consists of five categories, which are integrated and encompassed by core category *Outsiders in the Experts' World*. Seven key findings are identified, a number of which will be discussed in the following chapter.

CHAPTER SIX: DISCUSSION

> *The focus of medicine […] is the health of humanity.*
>
> *(Hutchinson & Brawer, 2011, p. 32)*

> *Life is not fragmented, as envisioned by modern science, but rather that all the pieces make up an interconnected whole.*
>
> *(Maoshing Ni, 1995, p. xiii)*

> *Being ill is another way of living, but by the time we have lived through illness we are living differently.*
>
> *(Frank, 2002, p. 3)*

The findings of the grounded theory *Outsiders in the expert's world* present *what* happens when people enter the social world of health care and take on a consumer role and *how* processes of interactions between consumers and experts are enacted. The contingent relationship between the *what* and the *how* (Charmaz, 2014) addresses the question, '*why* are consumers outsiders in the experts' world?' and provides the basis for this discussion chapter. The discussion focuses on three concepts identified from the key findings presented at the end of the previous chapter (Chapter 5). The concepts are culture shock, health literacy and bridging dichotomies in relation to power and decision-making. This discussion chapter situates the findings within the broader literature in relation to these concepts. The researcher reviewed the literature in each of these areas, sourcing literature from the following databases: Google Scholar, CINHAL and Scopus. Searches of the grey literature and ancestry searches were also conducted.

The discussion of culture shock likens consumers' experiences of entering the social world of health care to the experience of a traveller arriving in a foreign country. Cognitive responses to culture shock are intertwined with the social categorisation of people as consumers and peoples' perceptions of self within their consumer roles. Health literacy is foundational to what it means to be a health consumer. The concept of consumers' health literacy and their ability to participate in their health and health care is implicit throughout the following discussion, although it must be emphasised that health literate consumers are not necessarily empowered consumers. Study findings present dichotomies of ‘us and them’. In this discussion chapter, bridging dichotomies is discussed within the broader literature context in relation to the consumer-expert relationship and power balances and shared decision-making within that relationship.

Culture shock

When consumers unexpectedly enter the social world of health care they experience culture shock. Consumers experience the shock of a diagnosis (Glacken, Kernohan, & Coates, 2001; Kralik, Brown, & Koch, 2000) and the shock of suddenly being subjected to an unfamiliar culture (Edwards Lenkeit, 2014). Anthropologists use the term culture shock to describe feelings of disorientation, frustration and helplessness that a person encounters when they are subjected to an unfamiliar culture (Edwards Lenkeit, 2014). Culture shock involves two key processes: contact with or immersion in an unfamiliar culture; and loss of familiar social roles, cues and practices (Oberg, 1960). Edwards Lenkeit (2014) refers to the cultural environment of the social world of health care as a microculture consisting of physical objects, ideas, beliefs and institutional processes, which are unfamiliar to consumers. Additionally, technical terminology is used, which may be difficult for consumers to understand (Zeng-Treitler, Goryachev, Tse, Keselman, & Boxwala, 2008).

The term culture shock is most commonly used in reference to a person travelling to another country (Ward, Bochner, & Furnham, 2001). In the discussion here, the concept of culture shock is applied to consumers’ experiences of unexpectedly entering the social world of health care. When people make unexpected entrances into the social world of health care they leave their expectations of everyday life behind and take on a consumer role (Plummer, 2012). This means that consumers need to interpret, define and learn their new role within a new cultural environment while interacting with experts who belong to a different social group.

Unexpectedly entering the social world of health care is akin to “taking a first trip to a foreign country” (Ramsden, 1980, p. 289). The difference being, that a person taking a first trip to a foreign country is better prepared for their experience than a person making an unexpected entrance into the social world of health care. A trip to a foreign country is usually planned: departure and return dates are chosen; travellers will often have some knowledge of the language, norms and culture of the country they are visiting; and travellers will have an idea of what their budget will allow in relation to accommodation and other expenses. People do not have the luxury of preparing for their entrance into the social world of health care. People make unexpected entrances as a result of acute episodes or accidents, as findings in this study demonstrate. Non-acute episodes of illness may also lead to consumers making an entrance into the social world of health care. For example a routine visit to a general practitioner may lead to medical tests, treatments and a revolving door of visits to experts for which the consumer is unprepared.

Comparing international students’ experiences of culture shock (Egenes, 2012; Lombard, 2014; Zhou, Jindal-Snape, Topping, & Todman, 2008) to consumers’ experiences of their unexpected entrance into the social world of health care highlights similarities between the two. In both instances, cross-cultural contact provokes changes in individuals’ perceptions of identity and self, as evidenced in study findings and the literature (Kralik et al., 2000). Zhou (2008) presents a “cultural synergy framework” (p. 63) for understanding the processes involved in culture shock. Within the framework, cognitive responses to shock and adaptation are linked to the theoretical concept of social identification. The shock of unexpectedly entering the social world of health care and being classified as a consumer affects individual’s identity (Lombard, 2014). Classifying individuals into social groups is a process of social categorisation (Abrams & Hogg, 1990) in which individuals not only categorise others but also consider whether others belong to their own “in-group, or to some other, out-group” (Ward et al., 2001, p. 9).

In the seminal work *The Social System*, Parsons (1951) states that categorising people as ‘being sick’ is a social condition because it involves people entering into a socially constructed role. Although ‘the sick role’ categorises people, Parsons (1951) contends that consumers do not collectively form a sub-culture, because the undesirable state of being sick is not a motivating factor for membership to this group. Since Parson’s work (Parsons, 1951), the number of people with diagnosed illness has increased and the concept of consumer support groups has developed. The experience of being socially categorised as being sick is, therefore, not necessarily as isolating as Parson infers. Some consumers in this study, particularly parents of children with disabilities, cultivate support by seeking out and connecting with consumers experiencing similar situations. Interacting with others and/or being a member of a support group creates a sense of belonging that alleviates these consumers’ feelings of isolation and ‘normalises’ their situation. Findings in the literature show that joining a support group enables consumers to identify with others through shared experiences (Doran & Hornibrook, 2013; Thompson et al., 2014).

Although some consumers may not be members of support groups the experience of illness is not a solitary one. Personal accounts in the literature and through online social media, relate stories of consumers sharing the experience of illness with partners, family and friends (Frank, 2002; Plummer, 2012). In the context of learning their new role as consumers, participants in this study share their experience of illness with others through processes of acquiring knowledge and cultivating support. Reciprocal information sharing with friends supports consumers to acquire knowledge about their condition and treatment processes, which guides consumers in their interactions with experts, as presented in the category *Learning a new role* in Chapter 5: Findings.

Consumers in this study also cultivate support from among their social networks, which are predominantly made up of friends and members of church communities. Findings in this study highlight an absence of support from family members. Although, consumers were not directly posed the question about their marital status in either the demographic questionnaire or during data generation events, almost all participants revealed their marital status during interviews or during open discussions with other consumers during the digital storytelling workshop. Most consumer study participants do not have life partners and, apart from one participant whose digital story highlighted a large family support network, few participants referred to having family members to support them. The itinerant nature of the community in which the study was conducted may be a contributing factor to a lack of family support for consumers in this study. From the researcher's own experience of living in the itinerant community in which the study was conducted, anecdotal evidence shows that community members' children, parents and extended family are often not situated within geographical proximities. This factor, together with an absence of life partners among most of the participants, means that consumers rely on members of their social networks to provide support during periods of illness.

Consumers also share their experience of illness with experts. Of all the relationships that consumers have with experts, the relationship with their general practitioner is perhaps the most personal. Establishing meaningful relationships with general practitioners enables consumers to establish their presence within the social world of health care. Relationships are established over time and findings in this study highlight the elements of consumers' lives and illness that are shared with general practitioners: divorce, having children, depression, and the lows and highs of illness. Consumers feel vulnerable when facing illness and seek attachment to experts to help them feel safe. Establishing a meaningful relationship with a regular general practitioner is valuable in supporting consumers (Bogelund Frederiksen, Kragstrup, & Dehlholm-Lambertsen, 2010). Plummer (2012) refers to his shared experience of illness with his life partner as *"a joint illness, 'our illness'"* (Section 8, Para 2). This description can be just as aptly applied to the experience of illness that consumers share with members of their broader social networks and with experts.

When illness becomes the foundation for socially categorising consumers, individuals' perceptions of self cognitively shift (Charles, Gafni, & Whelan, 1997; Mozo-Dutton, Simpson, & Boot, 2012). A cognitive shift means accepting and integrating illness into one's life and "liv[ing] illness fully" (Frank, 2002, p. 3). Consumers in this study demonstrate living illness fully as evidenced by their responses to emotional fluctuations and changing perceptions of self during the unexpected entrance phase of the consumer experience. In a study of the impact of multiple sclerosis on perceptions of self, Mozo-Dutton et al. (2012) found that the onset of illness changed study participants' perceptions of their body. Similarly, in this study, changing perceptions of self attest to some consumers viewing their physical body differently after an unexpected entrance into the social world of health care. Some consumers are more circumspect, however, and their perceptions of their physical self do not match the ways in which others perceive them.

Although, the onset of illness can change consumers' perceptions of their body and self, this does not necessarily mean a loss of self (Mozo-Dutton et al., 2012). Rather elements of one's former self can still be preserved and even enhanced through the experience of illness. This process is beautifully described in Ken Plummer's (2012) account of his own illness in which he explains that, although his body became a 'thin body', a 'tired body', an 'encephalopathic body', a 'transformed body' and a 'new body', he remained an 'interactionist academic self'. Plummer's preservation of self enabled him to reflect on, give meaning to and write about his experience of illness. Similarly, despite changing perceptions of self, consumers in this study maintain their other selves as mothers, daughters, husbands and health professionals. For consumers who are also experts, the experience of illness adds another dimension to what it means to be an expert.

Socially categorising people as consumers signifies a divide between them and experts. Categorising people as consumers also suggests that all consumers are equal and should therefore be treated equally (Wenzel, 2004). Findings from this study suggest that consumers are not treated equally as evidenced by the dichotomies of 'us and them', which presented as an *in vivo* code in the data. Disparities in processes of interaction are noticeably different when interactions between consumers with mental illness and experts are compared to interactions between consumers, who have other conditions, and experts. For study participants with mental illness or participants who care for someone with mental illness, the dichotomy of 'us and them' is particularly salient. These participants feel stigmatised by experts. Dichotomies of "'us' from 'them'" are similarly expressed in the literature (Rusch, Angermeyer, & Corrigan, 2005, p. 530). Unlike the dichotomy of consumer versus expert, as expressed by consumers in this study, Rusch et al. (2005) refer to the separation of consumers with non-mental illness (us) from consumers who have been labelled with a mental illness (them). Social labels dichotomise; particularly when people are referred to as ‘being’ the label. Link and Phelan (2001) highlight that people who are diagnosed as having schizophrenia are often categorised as *being* schizophrenic whereas people diagnosed with cancer or diabetes are categorised as *having* cancer or diabetes.

Community discrimination and stigmatisation of mental illness have been identified in the literature as deterrents to individuals accessing care (Dinos, Stevens, Serfaty, Weich, & King, 2004; McCann & Clark, 2003). In some ways, fear of discrimination and stigmatisation are realised if consumers do bring themselves to access health care services. Organisational policies and procedures may discriminate against and/or stigmatise consumers (Corrigan, Markowitz, & Watson, 2004) and individual experts may bring their own biases to their role (McCann & Clark, 2003). An example from this study was the non-allocation of resources (mental health staff) in a public hospital Emergency Department on a Sunday, which discriminated against a consumer participant who was sent home and told to contact her general practitioner “next week” (A48r1). Although many factors influence allocation of resources (Link & Phelan, 2001), the inability of public organisations to provide adequate services for consumers with mental health discriminates against their needs, which in some instances may be as life threatening as a heart attack. Consumers who care for someone with mental illness also feel stigmatised. These study participants struggled to be heard by experts and expressed feelings of isolation. Health professionals’ stigmatisation of mental health consumers reinforces dichotomies of ‘us and them’ (McCann & Clark, 2003; Rusch et al., 2005; Stubbs, 2014) that results in consumers positioning themselves as ‘warriors at war’ with experts.

Health literacy

Low health literacy is a silent killer (Zarcadoolas, Pleasant, & Greer, 2006). The ability of consumers to participate in their health and health care requires them to be health literate. Health literacy is defined in many ways in the literature (Australian Bureau of

Statistics, 2006; "Compilation of Patient Protection and Affordable Care Act 2010," 2010; Kickbusch, Pelikan, Apfel, & Tsouros, 2013; Nielsen-Bohlman, Panzer, & Kindig, 2004; Ratzan & Parker, 2002; U.S. Department of Health and Human Services; World Health Organization, 2009). Although, there is no one consistent definition of health literacy, most definitions refer to one or more of the following: consumers' cognitive and social skills; consumers' capacity to access, understand and use information and services; and consumer decision-making and action taking in relation to health. The US Institute of Medicine report *Health literacy: A prescription to end confusion* (Nielsen-Bohlman et al., 2004) extends the definition of health literacy to recognise the importance of "health context" (p. 32) and the "shared function of cultural, social, and individual factors" (p. 32) to the individual's skills and levels of health literacy and to the individual's role in their own health.

Nutbeam (2000) identifies three levels and purposes of health literacy: functional, interactive and critical. The functional level relates to the basic reading and writing skills necessary for consumers to effectively function in a health context. The interactive level is a more advanced level of cognitive literacy and social skills that enables consumers to actively participate in their own health and health care. When consumers have achieved a critical level of health literacy, they have the ability to critically analyse and use information to enact behaviours that overcome structural barriers to health (Coulter, Parsons, & Askham, 2008; Nutbeam, 2000). Supporting consumers to achieve critical levels of health literacy is important in addressing health inequalities, encouraging consumers to actively participate in their health and health care, and in improving consumer health outcomes (Kripalani, Paasche-Orlow, Parker, & Saha, 2006).

Consumer participants in this study demonstrated and discussed their skills in accessing, understanding and using health information within the context of acquiring knowledge about their illness. This demonstrates critical levels of health literacy. Apart from one participant who had only been in the health consumer role for six months, at the time of data generation, all of the consumers in the study had been in the role for extended periods of time. Although the length of time a person has been a consumer may influence their skills in relation to accessing, understanding and using health information, there did not appear to be any noticeable differences between the skills of the ‘newest’ consumer and the skills of other consumer study participants.

Strategies to build consumer health literacy include disseminating health information to consumers and health education. In both of these areas, experts play a key role. Despite the increased availability of health information through the Internet and other sources, findings in this study provide evidence to suggest that experts are either a key or an important complimentary source of health information for consumers. Most consumers in this study use the Internet to access general health information and information about treatment and medication options relevant to their specific health conditions. Consumers, however, consciously question the quality of health information sourced from the Internet and, in most instances, will seek advice and/or discuss information with experts. The Internet as a supplementary source of information as opposed to a replacement for experts’ advice is identified in the literature (Higgins, Sixsmith, Barry, & Domegan, 2011). Experts have also increased their use of the Internet to obtain health and medical information. A systematic review of doctors’ usage of the Internet found that doctors use the Internet more than national averages across a range of Western developed countries (Masters, 2008), which means that doctors are potentially in a position to guide consumers to credible sources of online health information.

The advent of the digital age has provided an opportunity for distributing health information through a wider range of avenues. Websites, health portals and online virtual support groups provide computer-based means of disseminating information. Websites and health portals are helpful in reinforcing information provided by experts and can be more effective than printed information (Wofford, Smith, & Miller, 2005). Online virtual communities and electronic peer-to-peer health support groups are widely available and also provide mechanisms for sharing information, although the health and social benefits of such groups is unclear largely due to the lack of methodological rigour in research studies (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004). Although some consumers in this study referred to community groups as sources of support and information sharing, consumers did not refer to using online support groups.

Other electronic means of providing health information to consumers, such as mobile-phone texts, audio tapes and interactive digital television have been shown to be less effective in increasing consumer knowledge but are beneficial in improving consumers' confidence and ability to participate in health related decision-making processes (Coulter et al., 2008). Using electronic means to disseminate information, however, excludes consumers who do not have access to computers or electronic devices and consumers who cannot physically use, or do not know how to use, electronic devices. This reinforces social inequalities by excluding groups such as older persons, people with disabilities and those from low-income groups (Ming Wen, Rissel, Baur, & Simpson, 2011).

Every interaction between consumers and experts provides an opportunity for health education. Traditionally, health education within the consumer-expert relationship has focused on a pedagogical education approach in which experts defined the content (U.S. Department of Health and Human Services: Agency for Healthcare Research and Quality, 2014). Within consumer-centred approaches to health care, individualised education approaches address consumer defined values and needs. Consumer health education not only supports increased health literacy levels but also enables individuals to exert greater control over a broad range of health determinants (Nutbeam, 2000). Underlying experts' ability to increase consumers level of health literacy and to positively influence consumers' behaviour is the rapport that experts have with individual consumers (Curtis, 2011). A good rapport between consumers and experts also provides opportunities for consumers to educate experts as study findings suggest. Findings demonstrate that confident consumers are willing and able to confront dichotomies between them and experts in an attempt to educate experts in relation to ways of communicating. By providing direct feedback to experts, consumers can influence experts' communication skills and remind experts of the importance of humanising interactions.

It is not possible from the findings of this study to assert whether the relationship between consumers and experts has a direct bearing on consumer literacy and health outcomes.

Findings from this study do, however, express consumer sentiments about the value that consumers place on established relationships with experts, particularly general practitioners and/or specialist doctors. Findings within the context of ‘establishing relationships’ suggest that the longer the period of time that relationships between consumers and doctors have been established, the more relaxed and open consumers are with doctors. Within the consumer-expert relationship, experts’ can use their skills and knowledge to communicate effectively and advance consumers’ health literacy levels.

Bridging dichotomies

It is widely recognised that the relationship between consumers and experts is important for individuals’ health and the course of illness (Murtagh, 2009; Tsai, Pierce, & Papachristos, 2015). The relationship, however, is complex. Consumers are essentially non-voluntary participants in a relationship in which consumers struggle to define their roles. Although consumers may not define their role in terms of a collective consumer group, the consumer role is ‘universal’ because the institutional and social expectations and obligations placed on consumers are applied to all consumers regardless of demographics such as age, gender, occupation, ethnicity or status in other spheres (Morgan, 1982; Parsons, 1951).

Institutionally and societally, there is an expectation that consumers “want to “get well”” (Parsons, 1951, p. 437). But depending on the individual consumer’s condition, they cannot be expected to get well of their own volition; the consumer’s condition means that they must be taken care of. Consumers are also expected to seek expert advice and to cooperate with experts “in the process of trying to get well” (Parsons, 1951, p. 437). The decision to place one’s self into the care of experts acknowledges that consumers need and want the skills and expertise of health professionals. In seeking the care of experts, consumers have already willingly decided to accept the professional dominance of experts (Parsons, 1951; Plummer, 2012). Yet as findings in this study demonstrate, willingly seeking expert care does not necessarily result in care being provided willingly. For consumers to receive tailored care both consumers and experts must willingly and actively listen to the other and act accordingly.

Additionally, findings in relation to consumers cultivating support and dichotomies ‘between us and them’ demonstrate that experts sometimes alienate consumers, particularly carers. This demonstrates experts’ unwillingness to interact with consumers and to fulfil the role that consumers and society expects of them.

Unlike the consumer role, the expert’s role is “collectivity-oriented not self-oriented” (Parsons, 1951, p. 434). Collectively, health professionals form a culture, which comprises sub-cultures of professionals from professions such as nursing or psychology. Membership into these groups is a selective process, and educational processes, professional qualifications and social categorisation legitimise their roles. Experts are aware of their social identities and learn, develop and maintain their professional identities through formal education, their experience in their role and consumers’ expectations of their role (Biddle, 1986; Broderick, 1998; Haslam, 2014). Experts are proficient in separating their professional and personal identities, as highlighted in the introduction to Chapter 5. Consumers do not have the luxury of separating their identities. The manifestation of illness in the physical body is not separate to consumers’ other social identities; body and self are inextricably entwined.

As part of their role, experts are expected to apply their skills and knowledge to the problem of consumers’ illness. Experts are also expected to act for the consumer’s and the community’s welfare rather than for their own self-interests. There is an expectation that professional practice and evidence-based practice guide experts in their role and that they perform their role with emotional detachment and objectivity (Morgan, 1982). Additional to these core expectations are expectations associated with the model of consumer-expert relationship that dominates experts’ practice at any given time (Emanuel & Emanuel, 1992; Kaba & Sooriakumaran, 2007; Morgan, 1982).

While findings from this study do not explicitly refer to consumer-expert relationship models, they do highlight the range of approaches that experts incorporate into their practice when interacting with consumers. Findings relating to consumers’ attempts to cultivate support from experts, specifically in relation to mental illness, suggest that experts do not always interact with consumers within established frameworks (Duggan & Thompson, 2011; Lee &

Lin, 2010; Mead, Bower, & Hann, 2002). Rather, findings demonstrate that sometimes consumers are discriminated against or excluded from interactions with experts. Within an informative model of the consumer-expert relationship the expert's role is to provide consumers with facts that are not influenced by the experts' values (Emanuel & Emanuel, 1992). In the process of acquiring knowledge, consumers in this study describe how experts are a source of health information. Findings in this study are unable to support or negate findings in studies by both Bugge et al. (2006) and Roing and Holmstrom (2012), which found that experts' biases and values influence the provision of information to consumers. Findings from this study demonstrate that some experts use a relationship of mutuality approach, which is "described as a 'meeting between experts'" (Morgan, 1982, p. 54). Within this approach, consumers' values, preferences and knowledge combine with experts' clinical skills and knowledge to arrive at a negotiated approach that helps to bridge dichotomies between consumers and experts.

Balancing power

Until the early 1970s the traditional paternalistic model of health care dominated the 'doctor-patient' relationship in Western health care systems. Within this model the relationship is characterised by a dominant doctor interacting with a passive patient (Kaba & Sooriakumaran, 2007). Doctors act as consumer guardians and use their skills to determine the patient's condition and to prescribe tests and treatments that they consider best for the patient, who passively consents. While some emergency situations may still justify the use of this model, health care models have since evolved to incorporate other health professionals and consumers (Emanuel & Emanuel, 1992; Kaba & Sooriakumaran, 2007). A range of experts, including nurses, psychologists, and allied health professionals, are now instrumental in delivering health care (Bury, 2004). Under evolved models of care, the traditional paternalistic doctor-patient relationship has, in theory, transitioned to a partnering relationship, which is patient, person or consumer-centred (Duggan & Thompson, 2011; Lee & Lin, 2010; Mead et al., 2002). Evolved frameworks of health care aim to enable consumers to enact their authority, power and control within the consumer-expert relationship and thereby give new meaning to what it means to be in ‘the sick role’. In this study some consumers found that choosing a ‘squeaky wheel gets more oil’ approach enabled them to exert control within processes of interaction with experts. Gaining confidence and establishing relationships with experts over time also enables consumers to establish their presence and enact authority, power and control within the consumer-expert relationship. More often than not, however, findings in this study demonstrate that the concept of partnering relationships between consumers and experts is rhetorical.

Balint (1969) is generally credited with introducing the concept of patient-centredness (de Haes, 2006; Duggan et al., 2006; Murtagh, 2009) although literature refers to evidence of the principles of patient-centredness in the ancient Greek medical school of Cos (Stewart et al., 2000). The concept of consumer-centredness incorporates a range of dimensions that include: experts being respectful of and responsive to individual consumers values (Committee on Quality of Health Care in America, 2001); experts understanding and valuing what illness means for consumers; the concepts of “‘patient-as-person’ [and] ‘doctor-as-person’” (Mead et al., 2002, p. 285); and experts tailoring care to meet individual consumers’ needs and preferences (Rittenhouse & Shortell, 2009). Implicit, if not explicit, in concepts of patient-centredness is a shift towards consumer engagement in decision-making.

While policy and models of health care promote patient-centredness, enacting shared responsibility within the consumer-expert relationship is more fundamentally linked to individuals’ philosophical perspective of responsibility and interactions between the actors. Curtis (2011) asks, “Who is responsible […] in sickness and in health?” (p. 198) and presents four models of expert perceptions of consumer’s responsibility for their illness: consumer responsible for causing their illness; consumer responsible for solution; consumer not responsible for causing their illness; and consumer not responsible for solution. Experts’ beliefs about consumer’s responsibility will influence how experts ‘help’ consumers (Curtis, 2011). Equally, if consumers ask themselves the same question and identify their own beliefs about ‘who is responsible?’ for their illness and the potential solutions, this will influence how they participate in their own health. In the process of acquiring knowledge about their illness consumers may come to believe that they are responsibility for both the problem and the solution for their illness, as findings in this study demonstrate. Acquiring knowledge that leads to these conclusions does not necessarily lead to consumers achieving their desired outcomes of improved health. In the process of acquiring knowledge consumers sometimes spend too much money and time and ‘suffer greatly’, before seeking expert advice. The power of consumers is in knowing when to seek expert help and when to accept the benevolent power of experts (Plummer, 2012).

Empowering consumers to participate in their health and health care requires consumers to be health literate. Health literacy is critical to consumer empowerment but health literate consumers are not necessarily empowered. The two distinct concepts of health literacy and empowerment are interwoven, and as such should be considered in conjunction (Schulz & Nakamoto, 2013). Health literacy pertains to consumers’ knowledge and abilities to use information whereas empowerment is a subjective experience that impacts consumers’ motivation for action. Knowledge and abilities *per se* are not necessarily motivating (Schulz & Nakamoto, 2013). Empowerment is a relational construct that pertains to power, equity and control.

When consumers perceive that their role is valued within the consumer-expert relationship, consumers are motivated to actively participate in the relationship, including making decisions relating to their health care (Petriwskyj, Gibson, & Webby, 2014). Experts, who value the consumer’s role, promote shared responsibility for health and enable both actors to focus on what each can contribute to the relationship. Consumers are the experts on their own lives and health professionals have the skills and expertise to diagnosis and treat illness (Funnell & Anderson, 2003, 2004). The meaning that the consumer and the expert each ascribe to their own and the other’s expertise arises out of the interactional relationship between the two actors (Gergen, 1999; Mead, 1934; Stryker, 2008). From a traditional symbolic interactionism perspective, the interactional relationship is the locus of meaning (Mead, 1959). Meaning making is highlighted in confronting the dichotomy of ‘us and them’ in the findings. Stryker’s (2008) structural symbolic interactionism modifies the traditional approach and asserts, “society shapes self shapes social interaction" (p. 19). Within this approach social structures influence social interaction. Within a structural symbolic interactionist frame, the social world of health care is an organised system of social role relations between socially categorised groups of consumers and experts. Interactions between consumers and experts are therefore influenced by the structure of the health system and the roles assigned to consumer and expert actors interacting within the system. Evidence of the structural influence of the health system is presented in the findings. The structure of the system impacts the ability of consumers with mental illness to cultivate support and choose a voice, and demonstrates the ways in which experts enact their position of power within consumer-expert interactions.

Findings in this study suggest that the quality of interactions between consumers and experts is a key element in peoples' experience of being a consumer and literature supports these findings (Adams & Mueller, 2003; Adams & Drake, 2006). The concept of shared-decision making has overstepped a fundamental element in health care; consumers value and want experts who listen, respect and understand them. Information sharing and shared-decision making are processes based on objective (outside) elements that consumers and experts bring to the relationship. Listening, respect and understanding require consumers and experts to bring their subjective (inside) selves to the consumer-expert relationship. Engaging and connecting with each other requires consumers and experts to firstly engage with self.

Shared decision-making

Partnering with consumers and engaging consumers in decisions about their health care is now widely accepted and is a policy priority in many Western developed countries (Coulter, 2009; Entwistle, 2009). Additionally, in response to changes to health care models, the development of health care accreditation schemes and increases in the consumer rights and patient experience movements, health providers are required to engage consumers in planning, implementing and evaluating health care (Petriwskyj et al., 2014). In Australia, where consumer movements are relatively powerful, *Partnering with Consumers* is an overarching requirement for effective implementation of the National Safety and Quality Health Service Standards

(Australian Commission on Safety and Quality in Health Care, 2012). In Germany the establishment of the national research consortium *Patient as partner in medical decision-makin*g has increased research outputs and shared-decision making is now considered a quality indicator for medical care (Coulter, 2009).

An overview of shared decision-making approaches across a range of countries cites the USA, as the country in which ‘shared decision-making was invented’ (Coulter, 2009, p. 162). The focus on shared decision-making within the context of health care systems ignores the fact that consumers make daily choices and decisions regarding their health, that often have greater impact on their health outcomes than decisions made within the context of the consumer-expert relationship (Funnell & Anderson, 2004). Within the context of the consumer-expert relationship all parties must willingly participate in the process and agree to share information and treatment preferences with the aim of mutually agreeing on and sharing responsibility for treatment decisions (Charles et al., 1997; Röing & Holmström, 2012). Shared-decision making concepts and models are presented and discussed in the literature (Barry & Edgman-Levitan, 2012; Charles et al., 1997; Dy & Purnell, 2012; Flynn, Smith, & Vanness, 2006; Wirtz, Cribb, & Barber, 2006), however, findings from applied research studies provide evidence that applying shared-decision making models in practice is limited (Bugge et al., 2006; Stevenson, Barry, Britten, Barber, & Bradley, 2000).

Bugge, Entwistle and Watt (2006) identified instances where consumers and experts did not share information with each other that was potentially relevant to decision-making. Information that was not shared included information about the consumers’ health condition and information about treatment options. Similarly, in a study by Stevenson et al. (2000) of consumer-expert information sharing about medication in the general practice consultation, findings demonstrated that experts did not consistently present all medication options, did not consistently discuss dosages and side effects and in some instances referred to medication side effects as a technique for discouraging consumers from requesting antibiotics. When consumers in the study shared their beliefs and preferences for treatment options with their general practitioner, these were not generally taken seriously (Stevenson et al., 2000). In this grounded theory study findings demonstrate that confident consumers who actively confront the dichotomies of ‘us and them’ are willing to discuss and are able to negotiate with experts about their treatment preferences, particularly in relation to medication. Conversely, findings also show that in the process of acquiring knowledge, some consumers order their own medication online without first discussing this with medical experts or subsequently informing them.

The concept of shared-decision making depends on consumers and experts each having the same knowledge. There is an ethical requirement for experts to provide consumers with all treatment options and to present the advantages and disadvantages of each. Yet dichotomies of ‘us and them’ characterise asymmetrical power relations between consumers and experts, which influence shared decision-making processes. A study of shared decision-making among Swedish dentists (Röing & Holmström, 2012) found that dentists guide consumers towards the ‘right’ treatment choices. Dentists in the study openly admitted that their position of power enables them to consciously or subconsciously steer consumers toward the treatments that they, as experts, consider are best. While Roing and Holmstrom’s (2012) findings may be considered in negative terms of consumer disempowerment, the authors highlight the challenges that experts face in balancing their expertise with consumers’ right to choose. Similarly, the balancing act between what consumers want and what experts believe is the most appropriate course of action for an individual consumer at a given point in time is evidenced in confronting dichotomies of ‘us and them’ in this study. Shared-decision making is therefore a process of negotiation between consumers and experts with the aim of arriving at a decision that both actors agree to act on.

Chapter summary

This discussion chapter contextualises key study findings within the broader literature. The discussion focuses on the concepts of culture shock, health literacy and bridging dichotomies. Similarities between the shock of arriving in a foreign country and the culture shock of consumers’ unexpected entrances into the social world of health care are highlighted. The concept of health literacy is presented and its importance in consumers’ ability to participate in decisions regarding their health and health care are emphasised. The concept of bridging dichotomies examines balances of power and shared decision-making within the consumer-expert relationship and highlights that bridging dichotomies is a negotiated act between the actors. The following chapter presents the researcher’s conclusions to the study and provides a list of recommendations. The quality of the grounded theory research process and the grounded theory product are evaluated and the strengths and limitations of the study are also outlined.

CHAPTER SEVEN: CONCLUSION

> *Much of the populaity [sic] of grounded theory to sociologists and layman alike is that it deals with what is actually going on, not what ought to go on. ("It tells it like it is"). It gives traction over action; it makes sense, by making theoretical sense of common sense. And this has tremendous grab for people in the know.*
>
> *(Glaser, 1978, p. 14)*

> *Our life is all one human whole, and if we are to have any real knowledge of it we must see it as such. If we cut it up it dies in the process: and so I conceive that the various branches of research that deal with this whole are properly distinguished by change in the point of sight rather than by any division in the thing that is seen.*
>
> *(Cooley, 1956, Preface)*

The grounded theory *Outsiders in the experts' world* explains what is 'actually going on' in processes of interaction between consumers and experts in the social world of health care. The theory contributes to understandings and knowledge of what it means to be a *consumer* of healthcare – not a consumer who has been categorised as having diabetes, or cancer, or as a parent or carer of a person with mental illness or disabilities, or a consumer receiving care in a hospital or general practice setting or a consumer interacting with a specific health professional. The grounded theory provides a conceptual rendition of what it means to be a consumer interacting with experts in the social world of health care. Gaining insight into the substantive area of inquiry enables improved efficiencies in the delivery and quality of health care. Importantly, gaining insight into consumers' experience of interacting with experts also provides a foundation for considering relations and ways of interacting between consumers and experts that acknowledges and respects each actor's humanness.

This chapter presents the researcher's conclusions based on synthesis of the study findings and the discussion of key concepts from the findings within the broader literature. Recommendations for future actions are provided in the areas of policy, research, education and practice. Links between the research findings and the recommendations are also provided to ground these in the data. The final section of the chapter delivers an evaluation of the quality of both the research process and the research product (the grounded theory). Strengths and limitations of the study are also included in this section.

To be a health consumer means to be an outsider in the experts' social world of health care. Through all stages of the process, from a person's entrance into the world of health care to the point at which they may or may not receive tailored care, consumers are outsiders. Current health policy attempts to bridge dichotomies between consumer outsiders and expert insiders by introducing strategies and models of care that seek to place consumers and their families at the centre of care and to empower and support them to participate in their own health and health care (Australian Commission on Safety and Quality in Health Care (ACSQHC), 2011; Committee on Quality of Health Care in America, 2001; Johna & Rahman, 2011; Mastro, Flynn, & Preuster, 2014). A key impetus for the introduction of policies that aim to address dichotomies between consumers and experts is risk reduction. Reducing the risk of adverse events and increasing consumer safety within the context of health care is a win-win for both consumers and experts and the health systems within which they interact. Although a risk reduction approach to health care benefits consumers, approaches are largely policy driven and generally fail to consider what consumers really need and want from experts. Strategies represent what policy makers consider 'ought to go on'. Or do they?

Dichotomies fundamentally result from contradictory sets of underlying assumptions. Health systems are based on risk management and economic assumptions that favour transactional not relational interactions. Risk management strategies include evidence-based practices that are underpinned by positivist scientific knowledge, which favour a biomedical approach to interactions between experts and consumers. In contrast, consumer-centred approaches are based on bio-psychosocial perspectives that combine ethical values, consumers preferences, psychotherapeutic theories and negotiation theories (Bensing, 2000). Economic imperatives to achieve more with less impose structures that reward experts and health service providers for quantity of interactions over quality of interactions. Although the importance of the quality of interactions between consumers and experts is recognised, it is often measured through quantitative means.

The dichotomy of evidence-based practice and consumer-centred approaches to health care is reinforced by research and funding agendas that value positivistic evidence over interpretive perspectives; the idea being that ‘hard’ evidence should inform political and social practice and by implication, health practice (Hammersley, 2013). Yet by acknowledging an interpretive paradigm as equally valid, the relational aspect of interactions between consumers and experts can be acknowledged, understood, presented and incorporated into evidence-based practice approaches to health care that value both consumers’ experience and health professionals expertise, skills and experience. Qualitative research does gain credence when it is incorporated into a randomised control trial (Denzin, 2009) but this is small comfort for qualitative researchers who do not subscribe to participating in such studies. As it is, hierarchy of evidence tables uphold randomised control trials as the ‘gold standard’ of research and qualitative research methodologies rarely rate a mention (Birks & Mills, 2015).

If guidelines for assessing research and funding applications are the currency of quality, there is a comprehensive suite of criteria for assessing qualitative research available for use by policy makers. However, this requires more than just someone with appropriate research knowledge; it requires policy makers and institutions, including human research ethics committees to expand their thinking to incorporate qualitative understandings of health care and to value qualitative research for both its contribution to practice-based evidence and to intellectual and cultural endeavours that enrich the fabric of our society.

The positioning of qualitative research as inferior to quantitative research is reinforced in health profession education programs, which favour traditional positivist scientific ways of knowing (Eakin & Mykhalovskiy, 2005). This approach promotes positivist thinking about health care that health profession students then take with them into the social world of health care. Establishing curricula that incorporates teaching of both quantitative and qualitative research in equal proportions can broaden professionals’ minds to holistic ways of thinking about health and health care. It is not all doom and gloom however; there is a shift afoot.

Current trends in research suggest that the human qualitative aspect of health is gaining momentum, particularly at the consumer-expert interaction level (Brach, 2014; Johna & Rahman, 2011; The Beryl Institute, 2015) and that consumers are participating in their health care (Entwistle, 2009; Röing & Holmström, 2012; Stevenson et al., 2000). However, progress towards empowered individuals who are in control of their health and health care is slow (Foot et al., 2014) and care that is truly consumer-centred is the exception not the rule (Brach, 2014). Bridging dichotomies that exist between outsiders and insiders, means acknowledging consumers' and experts' differing perspectives, knowledge, skills, needs and desires in the process of improving consumers' experience of health care.

The wider debate about research funding is not just a qualitative versus quantitative debate but includes the idea that research agendas and government-funded research ensure equal representation of both. Multinationals and corporates have long been engaged in market research that incorporates qualitative methods. These organisations now recognise the value of consumers' qualitative experiences, beyond market research, and are embracing qualitative research at a rapid pace (Patino, Pitta, & Quinones, 2012) while policy makers are lagging behind. Governments can no long afford to ignore the value of consumers' qualitative experiences in government-funded areas such as health and education. Whereas quantitative research findings provide valuable data to meet government economic agenda requirements, knowledge and understanding of consumers' qualitative experiences and perspectives enable improved efficiencies in areas that specifically impact consumers. If governments in developed Western countries are genuinely committed to consumer-centred care, quantitative and qualitative research should be equally represented in research agendas and health professional education programs. Gripping tightly to a positivist notion of the world, that allows little room for what it means to be human, reflects narrow-mindedness and conservatism and in no way meets the needs of consumers in relation to research outcomes.

Interactions between consumers and experts occur within a social world of health whose very structures favour scientific assumptions and economic imperatives above interpretive perspectives and humanist imperatives. To achieve a 'healthier' more balanced health care system requires the willingness of all stakeholders to negotiate differing perspectives with the aim of arriving at shared perspectives. Through shared perspectives, the quality of actions and interactions at all levels of health care can be enhanced and efficiencies in the delivery of care improved. The findings of this study provide insights into consumers' perspectives of processes of interaction with experts. This provides an important foundation from which to commence negotiations. The perspectives underpinning evidence-based practice and consumer-centred care need to be negotiated and re-envisioned into new ways of delivering health care that do not dichotomise one perspective against the other but that integrate the true intent of each. The value of conclusions is in their ability to stimulate new beginnings, which is the intent here.

Recommendations

Providing actionable recommendations that link to study conclusions is a key component of a PhD study (Dale Bloomberg & Volpe, 2012) and unquestionably should be a component of all research in general. Recommendations from this research study relate to policy, research, education and practice. While some of these recommendations are not unprecedented, they reinforce and expand on recommendations presented elsewhere (Bensing, 2000; Calsyn & Oshima Lee, 2012; Eakin & Mykhalovskiy, 2005). Other recommendations are the researcher's own, although ownership is a loose term.

Policy (P)

1. Review the underlying philosophy of health policy. The emphasis on economic imperatives in health policy diminishes the relational aspect of interactions between consumers and experts. Creating and implementing health policies that incorporate evaluation of relational qualities of interactions makes economic sense. Healthy relations between consumers and experts improve consumer health outcomes, which, in turn, mean improved economic benefits for governments.
2. Implement a requirement that all funded randomised control trials include a qualitative component.

Research (R)

1. Conduct retrospective research into what would have assisted people in their transition to becoming a consumer.
2. Conduct more qualitative research in the substantive area of inquiry.
3. Conduct a formal grounded theory to identify the extent to which the theory *Outsiders in the expert's world* applies to other contexts; for example the social world of justice or the social world of welfare. Although some of the sub-categories of the grounded theory are specifically applicable to consumers within the social world of health care, the grounded theory presented in this thesis is transferable to other contexts. For example, the theory could be applied to processes of interaction between consumers and experts within the social world of justice, which may provide insights that have not been identified previously.

Education (E)

1. Ensure a balanced representation of qualitative and quantitative research paradigms and evidence in curricula for all health professionals.
2. Include advanced communication and negotiating skills in curricula for all health professionals.
3. Include the teaching of emotional, social and cognitive skills at all levels of education.
4. Include philosophy in primary and secondary school level curricula. Teaching and enabling children to understanding who they are, their place in the world, their values and their world views supports children to grow into more insightful adults. Having a better understanding of who we are as individuals, including the many roles we play, enables better communications and interactions with others, which ultimately would benefit society as a whole.

Practice (PR)

1. Introduce dedicated patient experience teams and positions within health workforce structures.

2. Develop consumer induction programs, with consumers, which meet consumers’ and individual health services’ needs.
3. Lengthen the time of a standard general practitioner consultation to enable experts to better engage with consumers.

Synergies between the categories of the grounded theory presented in Chapter 5: Findings and some of the above recommendations are presented in Figure 18.

Grounded theory category	Recommendation
Unexpected entrance	R1
Learning a new role	PR3
Establishing a presence	PR1, PR2
Confronting dichotomies of ‘us and them’	E2, E3, E4
Tailored care	E4, PR2, PR3

Figure 18: Matrix of grounded theory categories and recommendations

Evaluating quality

There is no one defined set of criteria for evaluating the quality of a grounded theory study. A range of criteria is, however, identified in the literature (Birks & Mills, 2011; Charmaz, 2014; Corbin & Strauss, 2008; Strauss & Corbin, 1990, 1998). Alternatively, researchers can select from criteria for assessing qualitative studies, which may also be applied to grounded theory studies (Creswell, 2007; Silverman, 2011b). The quality of a grounded theory research study has two components: the quality of the process and the quality of the product (the grounded theory). Selected domain criteria identified by Birks and Mills (2011) were used to assess the quality of the grounded theory process in this study, while Charmaz’s (2014) criteria of credibility, originality, resonance and usefulness were used for evaluating the quality of the grounded theory presented in this thesis. .

The domain criteria for evaluating quality of process include researcher expertise, methodological congruence and procedural precision (Birks & Mills, 2011). Researcher expertise does not infer that the researcher is an expert in the particular area being studied.

Rather researcher expertise incorporates experiential knowledge, generic skills, an open mind and a willingness to learn. The Prologue chapter of this thesis provides the reader with an overview of how and why the researcher came to undertake a PhD study and what was brought to the study at the outset. The researcher’s expertise, after undertaking a grounded theory research study, is demonstrated in the application of each of the essential grounded theory methods in the generation of the grounded theory presented in this thesis.

Methodological congruence is the integration of a researcher’s philosophical position, the study aims and the methodological approach used to achieve the aims. Undertaking a PhD study provided an opportunity for the researcher to purposefully consider her worldview and her position as researcher. The researcher situates herself within a constructivist paradigm in which the knower and the known are inseparable and reality is constructed. Within the researcher-researched relationship the researcher views herself as an interpreter of study participants stories and the data.

The aim of this study was to construct a grounded theory that explains the processes of interaction between consumers and experts. This has been achieved through an evolved grounded theory methodology underpinned by symbolic interactionism. Chapter 3: Methodology provides the reader with a detailed methodological map of processes used to achieve the aim. The outcome of the integration of the researcher’s philosophical position, the study aims and the methodological approach used to achieve the aims is the grounded theory *Outsiders in the experts’ world*. Procedural precision incorporates maintaining an audit trail, data management and procedural logic. An audit trail was maintained through the use of memo writing. The researcher established a procedure for labelling memos, which ensured that they were easily accessible and chronologically filed. The researcher used computer software and a system developed by Hahn (2008) for managing data. Using a structured system ensured that data were securely stored and easily identifiable and accessible. Flexibly using all of the essential grounded theory methods ensured procedural logic during the study process. Chapter 4: Method explains how each of the essential grounded theory methods were used in this study and provides graphic figures to illustrate the process.

Evaluating the grounded theory product provided the researcher with an opportunity to reflect on the credibility, originality, resonance and usefulness (Charmaz, 2014) of the grounded theory presented in this thesis. Presenting an overview of the evaluation process, outlines for the reader the ways in which the researcher believes the criteria have been met.

Credibility

The researcher’s intent, in relation to credibility, is to provide the reader with enough evidence from which to independently assess the grounded theory presented in this thesis (Charmaz, 2014). The credibility of this research study is established by linking the methods used to conduct the study to the study findings. This research study explored processes of interaction between consumers and experts using a variety of data collection and generation methods, including demographic questionnaires, interviews, consumers’ diary entries, digital stories, observation and fieldnotes. Using a range of methods enabled the researcher’s, consumers’, and consumer-researcher generated perspectives to be integrated, using constant comparative analysis processes.

The resultant grounded theory presented in the findings re-presents the researcher’s interpretive analysis of the data. The findings represent the story of consumers as *Outsiders in the experts’ world*. The use of purposive sampling including maximum variation, theoretical sampling and snowball sampling techniques (Patton, 2002) resulted in a sample of 32 participants. Having *many* participants increases accuracy and enhances credibility (Charmaz & Bryant, 2011). Although theses authors do not quantify ‘many’ it is argued that 32 participants is a substantial grounded theory sample. Throughout the story, participants’ voices are ‘heard’ through the use of direct quotes and images from digital stories, which demonstrate the grounding of the theory in the data. Throughout the findings, links are also established between direct data and/or concepts and the methods used to collect and generate data. Establishing these links demonstrates the researcher’s integration and interpretation of data associated with the differing perspectives of each method. Writing memos throughout the study ensured that the researcher maintained an audit trail of decision-making throughout the study and provided a retrospective ‘map’ of the development of the grounded theory. Having a chronological ‘bank’ of memos, together with a robust data management system, facilitated access to information and data that ensures the credibility of the grounded theory presented in Chapter 5: Findings.

Originality

The grounded theory *Outsiders in the experts’ world* provides new insight into what it means for consumers interacting with experts in the social world of health care. The theory is original as there have been no grounded theory studies conducted in this specific area. The originality of the theory also lies in the presentation of consumers who are not bound by illness categorisations and of interactions between consumers and experts that are not bound by specific health care settings, as is often the case in research involving consumers (See: Ferri et al., 2015; Goodwin & Happell, 2006; Larsen, Larsen, & Birkelund, 2013). Analysis and integration of data from this study generated a new abstract, conceptual rendering of the data that resulted in a grounded theory, which explains processes of interaction between consumers and experts.

Key findings from the study, which are discussed in the context of the broader literature include: theoretical and social concepts of culture shock and changing perceptions of self; health literacy; and bridging dichotomies of ‘us and them’ in relation to power balances and shared decision-making within consumer-expert relationships. Contextualising key findings in the literature refines and extends extent concepts and theories particularly in relation to people’s unpreparedness for taking on the consumer role. The new insights into this aspect of consumers’ experiences can therefore influence further research and the development of strategies that support people’s transition to the consumer role.

Resonance

The grounded theory presented in this thesis portrays and explains what processes of interaction between consumers and experts mean for consumers. The theory also reveals “taken-for-granted meanings” (Charmaz, 2014, p. 337) that some experts assign to both their role and the consumer role within processes of interaction. As highlighted in the Chapter 5:

Findings, there are experts who take their position of power for granted and assume that consumers do not want to know or do not need to know what is actually going on in relation to their health. The grounded theory presents a story of what is actually going on for consumers. Through the use of the storyline method the researcher has presented the data in a way that engages and involves the reader in the ‘story’ of what it means to be a consumer interacting with experts and which resonates for both consumers and experts.

The resonance of the theory for consumers was most poignantly evidenced in mid-2014 when the researcher presented the findings at the International Congress of Qualitative Inquiry. Following the presentation, one member of the audience commented, in particular, that the theory vividly recaptured her experience of the previous year when she was hospitalised with a broken hip. The member of the audience was herself an expert. As the audience member’s comments highlighted, and as the researcher has attempted to capture in the theory, the process of interaction between consumers and experts is universal and has little bearing on a consumer’s background, health condition or the setting in which they receive care. The full impact of the resonance of the theory is yet to be realised. This will be evidenced by how well health care stakeholders respond to the theory once the work is more widely disseminated.

Usefulness

To address the usefulness of a grounded theory, Charmaz (2014) prompts researchers to ask whether analysis of data offers “interpretations that people can use in their everyday worlds?” (p. 338). From a researcher’s subjective evaluation of their work, the answer is of course, ‘yes’. A range of stakeholders are involved in the everyday world of health care. This theory is useful to policy makers, health providers and consumer groups as it provides an intimate perspective of what it means to be a consumer in the social world of health care. Increased understandings of what it means to be a consumer enable stakeholders to consider the development and implementation of strategies, which support and strengthen the consumer role and consumers’ experience across all areas of health care. Additionally, a consumer perspective of interactions between them and experts provides experts with insight that may instigate reflection on the ways in which they interact with consumers. The theory *Outsiders in the experts' world* is a useful foundation from which to consider recommendations outlined above.

Strengths and limitations of the study

A key strength of this study is the sample size and the variation and scope of the data set. Data were collected and generated from 32 participants representing 23 consumers and nine experts. Variations in the consumer sample included a range of age groups, gender and representation of health conditions. Variations in the experts' sample included variations in age groups and representation of health professions. Eight of the nine experts were female. The scope of the data set includes data collected and generated via demographic questionnaires, interviews, consumer diaries, digital stories, observation and fieldnotes. The quantity of data collected and generated is included in Figure 10 in the thesis. The use of the essential grounded theory method of concurrent collection/generation and analysis of data enabled the researcher to pursue and to ascertain the 'hypothetical plausibility' of developing concepts and ideas in the field (Charmaz & Bryant, 2011).

The inclusion of a digital story telling workshop and the resultant digital stories also strengthen the study. Although health consumer digital story making is not a new phenomenon (Pilgrim Projects Limited, 2015) there is only a small amount of evidence in the literature (McKinstry, Hall, Hyett, & Kenny, 2014) of this method of data collection being used in research with health consumers. The workshop enabled consumers to learn new skills and to express themselves through means other than words only and without researcher input. The digital stories provided the researcher with personal and visually rich data that was comparatively analysed with data collected and generated through other methods.

The researcher's commitment to the act of memo writing resulted in her amassing a 'bank' of approximately 120 memos, which also strengthened the study. Having access to that quantity of decision-making records and thought patterns over the course of the study supported the development of the grounded theory.

Another strength of this study is the potential transferability of the findings. The grounded theory *Outsiders in the experts' world* is applicable across all health sectors and is transferable to other contexts in which consumers enter experts' social worlds, for example the justice system or the welfare system. In both of these systems, consumers make unexpected entrances and follow processes similar to the five categories presented in the theory. While theoretically the grounded theory from this study may be transferable to and applicable to other contexts, the scope of this study does not provide the opportunity for the researcher to extend the theory over and above the substantive area of the social world of health care. The applicability of the theory to broader environments has not, therefore, been substantiated.

No serious flaws limited this study. However, there are areas of the study where the researcher would have preferred processes to unfold differently. Theoretical sampling of participants is based on the developing theory. Early in the research process the developing theory guided the researcher to theoretically sample consumers with disabilities. Although the researcher made efforts to promote the study through community organisations that provide services to consumers with disabilities, efforts did not illicit new consumer participants. Attempts to theoretically sample consumers from this consumer group could have been extended to major cities. This, however, would have required additional funds for advertising and extended timelines. This last factor was the reason for the researcher not pursuing sampling of this consumer group further.

Another limitation of the study is the incomplete data set based on information obtained from demographic questionnaires. Participants who were recruited via snowball sampling did not complete demographic questionnaires, as this was not included in ethics applications. In retrospect, distribution of demographic questionnaires to these participants should have been included in the ethics application.

Chapter summary

This chapter concludes the thesis. The chapter presents the researcher's conclusions and recommendations from the study. Recommendations are made in the areas of policy, research, education and practice and are linked to the five categories of the grounded theory as applicable. Both the research process and the grounded theory product have been evaluated against criteria recognised in the literature. The chapter concludes with an overview of the strengths and limitations of the research study. The following Epilogue chapter provides the researcher's reflections on the research process and outlines key lessons learnt along the way. The Epilogue is written in the first person to reflect the researcher's subjective experience of conducting this study.

EPILOGUE

> *Many were the days that the dissertation felt like a hideous chronic disease.*
>
> *(Pieters & Dornig, 2013, p. 210)*

> *Now this is not the end. It is not even the beginning of the end. But it is, perhaps, the end of the beginning.*
>
> *Sir Winston Churchill, 1942*

I too am an outsider in the social world of health care. I rarely access mainstream health services; however the experience of undertaking this study has provided me with insight into what it means to be a health consumer. I am grateful that the study participants chose to share their stories with me and grateful that I could provide them with the opportunity. Consumers want their voices to be heard; to be able to tell their stories and for someone to listen. I listened to their stories, laughed with them and shared tears with, and for, them. Not only did the experience of undertaking this study provide me with insight into what it means to be a consumer, it also gave me insight into what it means to be a human being and what it means to be me.

When I think back to the person I was when I started this study I can appreciate what I have learnt and achieved. My most valuable lessons have been patience and perseverance and that at the end of the day, no matter how much support and encouragement I had from people around me, it was up to me to do the work. Listening to people's stories throughout the study really highlighted this last point. Some participants willingly relinquish their responsibility for their own health condition and just want someone to 'fix them'. While others take whatever support they can get but willingly take responsibility for their health and their role in improving and managing their condition. The strength and courage of those study participants is truly inspiring.

During the writing of the Discussion chapter of the thesis I reverted to writing with 'actual' pen and paper. I grew up mostly in the pre-computer era. Using pen and paper, is for me, a more intimate writing process than typing words on a keyboard that are presented on a screen and then printed on paper. The intimacy and immediacy of pen and paper enabled me to express my thoughts more freely and enabled the process of analysis to flow. This does not mean that the words I wrote on paper are the exact ones that appear in the Discussion chapter. Rather, the process of writing on paper enabled the words to appear in the Discussion.

Until I arrived toward the end of the thesis I was satisfied with my decision to use the term consumer to describe people who access health services. I recognise that I was influenced by the use of the term consumer in Australian policy and my personal belief that the term patient infers passivity, which excluded it as an option. Although I was satisfied with my original justification for using ‘consumer’, as I approached the end of the thesis the term consumer began to lose its appeal. Examining the literature around terminology usage for Chapter 2 highlighted the economic theory origins of the term consumer and this no longer sits comfortably with me. I believe that a philosophical perspective that values human relations as its core, should drive health care systems; approaching health care from a relational perspective will result in not only economic benefits, but also better relations between consumers and experts and improved consumer health outcomes. Socially categorising people labels them and sometimes dictates who they are and can influence how they behaviour. I think that the use of the term ‘people who access health services’ is much more appropriate, although a bit cumbersome, and in retrospect I would have used that term throughout the thesis if I had known then what I know now.

In retrospect, I also wish I had incorporated a process that enabled participants to evaluate their participation in the research study. This would have contributed to my evaluation of the research process of this study. Evaluation data would have also enabled me to identify area for improving future research studies. It is a lesson learnt!

The experience of undertaking this research study has been amazing and as it comes to an end and I consider my future I am reminded of the song lyrics to New York New York, “If I can make it there, I’ll make it anywhere”. There were plenty of times during the research study that I felt like I would never make it. Now as I make my way toward the end of the PhD experience I know that I can achieve almost anything. I also have a greater understanding of what it means to be a health consumer and I have greater empathy and compassion for people living with illness. I am grateful for the opportunity of undertaking a PhD and of listening to my study participants' stories.

REFERENCES

Abrams, D., & Hogg, M. (1990). *Social identity theory: Constructive and critical advances*. Hemel Hempstead, England: Harvester Wheatsheaf.

Adams, A., & Mueller, H. (2003). Chiropractic management of a patient with severe chronic back pain complicated by atypical Scheuermann's disease: a case report. *Journal of the American Chiropractic Association, 40*(9), 34-38.

Adams, J., & Drake, R. (2006). Shared decision-making and evidence-based practice. *Community Mental Health Journal, 42*(1), 87-105. doi: 10.1007/s10597-005-9005-8

Aldiabat, K., & Le Navenec, C.-L. (2011). Philosophical roots of classical grounded theory: its foundations in symbolic interactionism. *The Qualitative Report, 16*(4), 1063-1080.

Angell, J. (1907). The province of functional psychology. *The Psychological Review, 14*(2), 61-91.

Anhang Price, R., Elliott, M., Zaslavsky, A., Hays, R., Lehrman, W., Rybowski, L., . . . Cleary, P. (2014). Examining the role of patient experience surveys in measuring health care quality. *Medical Care Research and Review*. doi: 10.1177/1077558714541480

Annells, M. (1996). Grounded theory method: Philosphical perspectives, paradigms of inquiry, and postmodernism. *Qualitative Health Research, 6*(3), 379-393.

Australian Bureau of Statistics. (2006). *Adult literacy and life skills survey: User guide*. (4228.0.55.002). Canberra, Australia: Australian Bureau of Statistics.

Australian Commission on Safety and Quality in Health Care. (2012). Review of patient experience and satisfaction surveys conducted within public and private hospitals in Australia. Australia: Australian Commission on Safety and Quality in Health Care.

Australian Commission on Safety and Quality in Health Care (ACSQHC). (2011). National Safety and Quality Health Service Standards. Sydney: ACSQHC.

Australian Commission on Safety and Quality in Health Care (ACSQHC). (2014). Health literacy: Taking action to improve safety and quality. Sydney: ACSQHC.

Badley, G. (2011). Six characters in search of an author: A qualitative comedy in the making. *Qualitative Inquiry*, 1-9. doi: 10.1177/1077800411425332

Balint, E. (1969). The possibilities of patient-centered medicine. *Journal of the Royal College of General Practitioners, 17*(82), 269-276.

Banks, M. (2007). *Using visual data in qualitative research* (U. Flick Ed.). London: SAGE Publications Ltd.

Barry, M., & Edgman-Levitan, S. (2012). Perspective: Shared decision making - The pinnacle of patient-centered care. *New England Journal of Medicine, 366*(9).

Bensing, J. (2000). Bridging the gap. The separate worlds of evidence-based medicine and patient-centered medicine. *Patient Education and Counseling, 39*, 17-25.

Biddle, B. (1986). Recent development in role theory. *Annual Review of Sociology, 12*, 67-92.

Birks, M. (2012). Memoing in grounded theory with Associate Professor Melanie Birks. YouTube.

Birks, M., Chapman, Y., & Francis, K. (2008). Memoing in qualitative research: Probing data and processes. *Journal of Research in Nursing, 13*(1), 68-75.

Birks, M., & Mills, J. (2011). *Grounded Theory: A Practical Guide*. Los Angeles: Sage.

Birks, M., & Mills, J. (2015). *Grounded theory: A practical guide*. London: Sage.

Blackburn, E. (1991). Structure and function of telomeres. *Nature, 350*(6319), 569-573.

Blumer, H. (1969). *Symbolic Interactionism: Perspective and Method*. Berkeley: University of California Press.

Bogelund Frederiksen, H., Kragstrup, J., & Dehlholm-Lambertsen, B. (2010). Attachment in the doctor-patient relationship in general practice: A qualitative study. *Scandinavian Journal of Primary Health Care, 28*(3), 185-190.

Bolster, D., & Manias, E. (2010). Person-centred interactions between nurses and patients during medication activities in an acute hospital setting: Qualitative observation and interview study. *International Journal of Nursing Studies, 47*, 154-165.

Brach, C. (2014). A daughter's frustration with the dearth of patient- and family-centered care. *Patient Experience Journal, 1*(1), 43-47.

Broderick, A. (1998). Role theory, role management and service performance. *Journal of Services Marketing, 12*(5), 348-361.

Bryant, A. (2009). Grounded theory and pragmatism: The curious case of Anselm Strauss. *Forum: Qualitative Social Research, 10* (No. 3, Art. 2).

Bryant, A., & Charmaz, K. (2007a). Grounded theory in historical perspective: An epistemological account. In A. Bryant & K. Charmaz (Eds.), *The Sage handbook of grounded theory*. LA: Sage Publications.

Bryant, A., & Charmaz, K. (2007b). Introduction. Grounded theory research: Methods and practice. In A. Bryant & K. Charmaz (Eds.), *The SAGE Handbook of grounded theory* (pp. 1-28). London, UK: Sage Publications Ltd.

Bugge, C., Entwistle, V., & Watt, I. (2006). The significance fro decision-making of information that is not exchanged by patients and health professionals during consultations. *Social Science & Medicine, 63*, 2065-2078.

Bury, M. (2004). Researching patient-professionals interactions. *Journal of Health Services Research & Policy, 9*(Suppl 1), S1:48-S41:54.

Cahill, J., Barkham, M., Hardy, G., Gilbody, S., Richards, D., & Bower, P. (2008). A review and critical appraisal of measures of therapist-patient interactions in mental health settings. *Helath Technology Assessment, 12*(24).

Calsyn, M., & Oshima Lee, E. (2012). Alternatives to fee-for-service payments in health care: Moving from volume to value. USA: Centre for American Progress.

Care Quality Commission. (2010). Essential standards of quality and safety. UK: Care Quality Commission.

Chamberlain-Salaun, J., Mills, J., & Park, T. (2011). Mental health nurses employed in Australian general practice: Dimensions of time and space. *International Journal of Mental Health Nursing, 20*(2), 112-118. doi: 10.1111/j.1447-0349.2010.00723.x

Chamberlain-Salaun, J., Mills, J., & Usher, K. (2013a). Linking symbolic interactionism and grounded theory methods in a research design: From Corbin and Strauss' assumptions to action. *SAGE Open, 3*. doi: 10.1177/2158244013505757

Chamberlain-Salaun, J., Mills, J., & Usher, K. (2013b). Terminology used to describe health care teams: an integrative review of the literature. *Journal of Multidisciplinary Healthcare, 6*, 65-74.

Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). *Social Science & Medicine, 44*(5), 681-692.

Charmaz, K. (1995). Grounded theory. In R. Harre, J. Smith, & L. Van Langenhove (Eds.), *Rethinking Methods in Psychology* (pp. 27-49). London: Sage Publications.

Charmaz, K. (2003). Grounded theory: Objectivist and constructivist methods. In N. Denzin & Y. Lincoln (Eds.), *Strategies of Qualitative Inquiry* (2nd ed., pp. 249-291). Thousand Oaks, California: Sage Publications.

Charmaz, K. (2005). Grounded theory in the 21st century: Applications for advancing social justice studies. In N. Denzin & Y. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed., pp. 507-535). Thousand Oaks, CA: Sage Publications, Inc.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London: Sage Publications.

Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). LA: Sage Publications Ltd.

Charmaz, K., & Bryant, A. (2011). Grounded theory and credibility. In D. Silverman (Ed.), *Qualitative research: Issues of theory, method and practice* (3rd ed., pp. 291-309). London, UK: SAGE Publications Ltd.

Charon, J. (2007). *Symbolic Interactionism: An introduction, an interpretation, an integration* (Ninth ed.). New Jersey: Pearson Prentice Hall.

Cheong, L., Armour, C., & Bosnic-Anticevich, S. (2013). Multidisciplinary collaboration in primary care: through the eyes of patients. *Australian Journal of Primary Health, 19*, 190-197.

Christiansen, A. (2011). Storytelling and professional learning: A phenomenographic study of students' experience of patient digital stories in nurse education. *Nurse Education Today, 31*, 289-293.

Clarke, A. (1991). Social worlds / arenas theory as organizational theory. In D. Maines (Ed.), *Social organization and social process: Essays in honor of Anselm Strauss* (pp. 119-158). Hawthorne, NY: Aldine de Gruyter.

Clarke, A. (2003). Situational analyses: Grounded theory mapping after the postmodern turn. *Symbolic Interaction, 26*(4), 553-576.

Clarke, A. (2005). *Situational analysis: Grounded theory after the postmodern turn*. Thousand Oaks, CA: Sage Publications.

Clarke, A. (2007). Social worlds. In G. Ritzer (Ed.), Blackwell Encyclopedia of Sociology. Blackwell Publishing: Blackwell Reference Online. Retrieved from http://www.sociologyencyclopedia.com.elibrary.jcu.edu.au/subscriber/uid=3569/tocnode?query=symbolic+interactionism&widen=1&result_number=52&from=search&id=g9781405124331_yr2010_chunk_g978140512433125_ss1-188&type=std&fuzzy=0&slop=1. doi: 10.1111/b.9781405124331.2007.x

Cleary, M., Horsfall, J., & Hayter, M. (2014). Editorial - Qualitative research: quality results? *Journal of Advanced Nursing, 70*(4), 711-713. doi: DOI: 10.1111/jan.12172

Cleary, P., Edgman-Levitan, S., Roberts, M., Moloney, T., McMullen, W., Walker, J., & Delbanco, T. (1991). At the intersection of health, health care and policy. *Health Affairs, 10*(4), 254-267.

Committee on Quality of Health Care in America. (2001). *Crossing the quality chasm: A new health system for the 21st Century*. Washington, D.C.: National Academy Press.

Compilation of Patient Protection and Affordable Care Act 2010, Title V - Health care workforce: Subtitle A - Purpose and definitions, Office of the Legislative Counsel for the U.S House of Representatives, § Sec. 5002 (21) (2010 May 1, 2010).

Cooley, C. (1956). *The two major works of Charles H. Cooley: Social organization and Human nature and the social order*. Glencoe, Illinois: The Free Press.

Corbin, J., & Strauss, A. (1990). Grounded theory research: Procedures, canons and evaluative criteria. *Zietschrift fur Soziologie, 19*(6), 418-427.

Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing Grounded theory* (3rd ed.). Los Angeles: Sage Publications.

Corrigan, P., Markowitz, F., & Watson, A. (2004). Structural levels of mental illness stigma and discrimination. *Schizophrenia Bulletin, 30*(3), 481-491.

Coulter, A. (2009). What's happening around the world? In A. Edwards & G. Elwyn (Eds.), *Shared decision-making in health care* (2nd ed., pp. 159-163). Oxford, UK: Oxford University Press.

Coulter, A., Parsons, S., & Askham, J. (2008). *Policy Brief: Where are the patients in decision-making about their own care?* Paper presented at the WHO European Ministerial Conference on Health Systems: "Health systems. Health and wealth", Tallinn, Estonia.

Creswell, J. (2007). *Qualitative inquiry and research design: Choosing among five approaches* (2nd ed.). Thousand Oaks, CA, USA: Sage Publications, Inc.

Creswell, J. (2014). *Research design: Qualitative, quantitative and mixed methods approaches* (4th ed.). Thousand Oaks, CA: SAGE Publications Inc.

Curtis, K. (2011). Health behavior and effective patient education. In C. Davis (Ed.), *Patient practitioner interaction: An experiential manual for developing the art of health care* (pp. 197-209). Thorofare, NJ, USA: Slack Incorporated.

Dale Bloomberg, L., & Volpe, M. (2012). *Completing your qualitative dissertation: A road map from beginning to end* (2nd ed.). Thousand Oaks, CA, USA: SAGE Publications, Inc.

de Haes, H. (2006). Dilemmas in patient centredness and shared decision making: A case for vulnerability. *Patient Education and Counseling, 62*, 291-298.

Deber, R., Kraetschmer, N., Urowitz, S., & Sharpe, N. (2005). Patient, consumer, client, or customer: what do people want to be called? *Health Expectations, 8*, 345-351.

Dell'api, M., Rennick, J., & Rosmus, C. (2007). Childhood chronic pain and health care professional interactions: shaping the chronic pain experiences of children. *Journal of Child Health Care, 11*(4), 269-286.

Denzin, N. (1985). Emotion as lived experience. *Symbolic Interaction, 8*(2), 223-240.

Denzin, N. (1992). *Symbolic interactionism and cultural studies: The politics of interpretation*. Oxford, UK: Blackwell.

Denzin, N. (2009). The elephant in the living room: or extending the conversation about the politics of evidence. *Qualitative Research, 9*, 139-160.

Department of Health. (2013). The NHS Outcomes Framework 2014/15. UK: Department of Health.

Dew, K. (2007). A health researcher's guide to qualitative methodologies. *Australian & New Zealand Journal of Public Health, 31*(5), 433-437.

Digby, A. (1997). The patient's view. In I. Loudon (Ed.), *Western medicine: An illustrated history* (pp. 291-305). Oxford, UK: Oxford University Press.

Dinos, S., Stevens, S., Serfaty, M., Weich, S., & King, M. (2004). Stigma: the feelings and experiences of 46 people with mental illness. *British Journal of Psychiatry, 184*, 176-181.

Dodd, S. (2002). Metaphors and meaning: A grounded cultural model of US entrepreneurship. *Journal of Business Venturing, 17*, 519-535.

Doran, F., & Hornibrook, J. (2013). Women's experiences of participation in a pregnancy and postnatal group incorporating yoga and facilitated group discussion: A qualitative evaluation. *Women and Birth, 26*(1), 82-86.

Drake, R., Deegan, P., & Rapp, C. (2010). The promise of shared decision making in mental health. *Psychiatric Rehablitation Journal, 24*(1), 7-13.

Drew, P., Chatwin, J., & Collins, S. (2001). Conversation analysis: a method for research into interactions between patients and health-care professionals. *Health Expectations, 4*, 58-70.

Duggan, A., & Thompson, T. (2011). Provider-patient interaction and related outcomes. In T. L. Thompson, R. Parrott, & J. Nussbaum (Eds.), *The Routledge handbook of health communication*. New York, NY: Routledge.

Duggan, P., Geller, G., Cooper, L., & Beach, M. (2006). The moral nature of patient-centeredness: Is it "just the right thing to do"? *Patient Education and Counseling, 62*, 271-276.

Dunleavy, P. (2014). Designing 'attention points' in academic work: Four principles for improving tables, graphs, charts and diagrams. Retrieved from http://blogs.lse.ac.uk/impactofsocialsciences/2014/04/03/designing-attention-points-in-academic-work/

Dy, S., & Purnell, T. (2012). Key concepts relevant to quality of complex and shared decision-making in health care: A literature review. *Social Science & Medicine, 74*, 582-587.

Eakin, J., & Mykhalovskiy, E. (2005). Teaching against the grain: The challenges of teaching qualitative research in the health sciences. *Forum: Qualitative Social Research, 6*(2, Art. 42).

Edwards Lenkeit, R. (2014). *High heels and bound feet: And other essays on everyday anthropology*. Long Grove, IL, USA: Waveland Press.

Egenes, K. (2012). Health care delivery through a different lens: The lived experience of culture shock while participating in an international educational program. *Nurse Education Today, 32*, 760-764.

Emanuel, E., & Emanuel, L. (1992). Four models of the physician-patient relationship. *The Journal of the American Medical Association, 267*(16), 2221-2229.

Engel, G. (1977). The need for a new medical model: A challenge for biomedicine. *Science, 196*(4286), 129-136.

Entwistle, V. (2009). Patient involvement in decision-making: The importance of a broad conceptualization. In A. Edwards & G. Elwyn (Eds.), *Shared decision-making in health care: Achieving evidence-based patient choice* (2nd ed., pp. 17-22). Oxford, UK: Oxford University Press.

Eysenbach, G., Powell, J., Englesakis, M., Rizo, C., & Stern, A. (2004). Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *BMJ, 328*(1166). doi: http://dx.doi.org.elibrary.jcu.edu.au/10.1136/bmj.328.7449.1166

Faux, S., & Young Seideman, R. (1996). Health care professionals and their relationships with families who have members with developmental disabilities. *Journal of Family Nursing, 2*(2), 217-238.

Ferri, P., Muzalupo, J., & Di Lorenzo, R. (2015). Patients' perception of dignity in an Italian general hospital: a cross-sectional analysis. *Bmc Health Services Research, 15*(41). doi: DOI 10.1186/s12913-015-0704-8

Fine, G. (1993). The sad demise, mysterious disappearance, and glorious triumph of symbolic interactionism. *Annual Review of Sociology, 19*, 61-87.

Flynn, K., Smith, M., & Vanness, D. (2006). A typology of preferences for participation in healthcare decision making. *Social Science & Medicine, 63*, 1158-1169.

FNQDocs. Our members. Retrieved 22 September 2014, from http://www.fnqdocs.org.au/www/content/default.aspx?cid=704&fid=666

Foot, C., Gilburt, H., Dunn, P., Jabbal, J., Goodrich, J., Buck, D., & Taylor, J. (2014). People in control of their own health and care: The state of involvement. London, UK: The King's Fund.

Frank, A. (2002). *At the will of the body: Reflections on illness*. New York: Mariner Books.

Frank, A. (2004). *The renewal of generosity: illness, medicine, and how to live*. Chicago: The University of Chicago Press.

Funnell, M., & Anderson, R. (2003). Patient empowerment: a look back, a look ahead. *The Diabetes Educator, 29*(3), 454-464.

Funnell, M., & Anderson, R. (2004). Empowerment and self-management of diabetes. *Clinical Diabetes, 22*(3), 123-127.

Gergen, K. (1999). *An invitation to social constrution*. London, UK: SAGE Publications Ltd.

Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Methods of data collection in qualitative research: interviews and focus groups. *British Dental Journal, 204*(6), 291-295.

Glacken, M., Kernohan, G., & Coates, V. (2001). Diagnosed with Hepatitis C: a descriptive exploratory study. *International Journal of Nursing Studies, 28*, 107-116.

Glaser, B. (1978). *Theoretical sensitivity*. San Francisco: University of California.

Glaser, B. (1992). *Basics of grounded theory analysis: Emergence vs. forcing.* Mill Valley, CA: Sociology Press.

Glaser, B. (1999). The future of grounded theory. *Qualitative Health Research, 9*(6), 836-845.

Glaser, B. (2002). Constructivist grounded theory? *Forum: Qualitative Social Research, 3*(3, Art. 12), http://www.qualitative-research.net/index.php/fqs/article/view/825/1792 - gcit.

Glaser, B. (2004). Remodeling grounded theory. *Forum: Qualitative Social Research, 5*(2, Art. 4).

Glaser, B. (2012). No preconception: the dictum. *Grounded Theory Review: An international journal, 11*(2), 1-8.

Glaser, B., & Holton, J. (2007). Remodeling grounded theory. *Hoistorical Social Research / Historische Sozialforschung, Supplement 7*, 47-68.

Glaser, B., & Strauss, A. (1965). *Awareness of dying*. Chicago: Aldine Publishing Co.

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

Glaser, B., & Strauss, A. (1968). *Time for dying*. Chicago, Illinois: Aldine Publishing Company.

Gobo, G. (2011). Ethnography. In D. Silverman (Ed.), *Qualitative research: issues of theory, method and practice* (3rd ed.). Los Angeles: Sage Publications.

Goffman, E. (1959). *The presentation of self in everyday life*. New York: Doubleday Anchor Books.

Goodwin, V., & Happell, B. (2006). In our words: Consumers' views on the reality of consumer participation in mental health care. *Contemporary Nurse, 21*, 4-13.

Griffin, E. (2012). *A first look at communication theory* (8th ed.). New York, NY: McGraw-Hill.

Guba, E., & Lincoln, Y. (1989). *Fourth generation evaluation*. Newbury Park, CA, USA: Sage Publications.

Hahn, C. (2008). *Doing qualitative research using your computer: a practical guide*. London: Sage Publications Ltd.

Hammersley, M. (2013). *The myth of research-based policy & practice*. London, UK: SAGE Publications Ltd.

Hammersley, M., & Atkinson, P. (2007). *Ethnography: Principles in practice*. Taylor & Francis e-Library: Routledge.

Haslam, S. (2014). Making good theory practical: Five lessons for an applied social identity approach to challenges of organizational, health, and clinical psychology. *British Journal of Social Psychology, 53*, 1-20. doi: 10.1111/bjso.12061

Health Canada. (2015). Health Canada. Retrieved 6 February 2015, from http://www.hc-sc.gc.ca/index-eng.php

Health Consumers Queensland. (2012). *Consumer and Community Engagement Framework*. Queensland: Queensland Government.

Henderson, A., & Henderson, P. (2010). The recognition and valuing of patient knowledge: a way forward. *International Journal of Consumer Studies, 34*, 613-616.

Higgins, O., Sixsmith, J., Barry, M., & Domegan, C. (2011). A literature review on health information-seeking behaviour on the web: a health consumer and health professional perspective. Stockholm: European Centre for Disease Prevention and Control (ECDC).

Hoare, K., Mills, J., & Francis, K. (2012). Dancing with data: An example of acquiring theoretical sensitivity in a grounded theory study. *International journal of nursing practice, 18*(3), 240-245.

Holton, J. (2007). The coding process and its challenges. In A. Bryant & K. Charmaz (Eds.), *The SAGE Handbook of grounded theory* (pp. 265-290). London, UK: SAGE Publications Ltd.

Howell, D., Hardy, B., Boyd, C., Ward, C., Roman, E., & Johnson, M. (2014). Community palliative care clinical nurse specialists: a descriptive study of nurse-patient interactions. *International Journal of Palliative Nursing, 20*(5), 246-253.

Hunter, A., Murphy, K., Grealish, A., Casey, D., & Keady, J. (2011). Navigagting the grounded theory terrain. Part 1. *Nurse Researcher, 18*(4), 6-10.

Hutchinson, T., & Brawer, J. (2011). The challenge of medical dichotomies and the congruent physician-patient relationship in medicine. In T. Hutchinson (Ed.), *Whole person care: A new paradigm for the 21st Century* (pp. 31-43). New York: Springer.

Jangland, E., Larsson, J., & Gunningberg, L. (2011). Surgical nurses' different understandings of their interactions with patients: a phenomenographic study. *Scandinavian Journal of Caring Sciences, 25*, 533-541.

Johna, S., & Rahman, S. (2011). Humanity before science: Narrative medicine, clinical practice, and medical education. *The Permanente Journal, 15*(4), 92-93.

Kaba, R., & Sooriakumaran, P. (2007). The evolution of the doctor-patient relationship. *International Journal of Surgery, 5*, 57-65.

Kickbusch, I., Pelikan, J., Apfel, F., & Tsouros, A. (2013). Health Literacy: The solid facts *WHO Solid Facts*. Copenhagen, Denmark: World Health Organization: Regional office for Europe.

Kirmayer, L. (1992). The body's insistence on meaning: Metaphor as presentation and representation in illness experience. *Medical Anthropology Quarterly, 6*(4), 323-346.

Kitson, A., Marshall, A., Bassett, K., & Zeitz, K. (2013). What are the core elements of patient-centred care? A narrative review and synthesis of the literature from helath policy, medicine and nursing. *Journal of Advanced Nursing, 69*(1).

Kralik, D., Brown, M., & Koch, T. (2000). Women's experiences of 'being diagnosed' with a long-term illness. *Journal of Advanced Nursing, 33*(5), 594-602.

Kripalani, S., Paasche-Orlow, M., Parker, R., & Saha, S. (2006). Introduction: Advancing the field of health literacy. *Journal of General Internal Medicine, 21*(8), 804-805.

Lammers, J., & Happell, B. (2003). Consumer participation in mental health services: looking from a consumer perspective. *Journal of Psychiatric and Mental Health Nursing, 10*, 385-392.

Larsen, L., Larsen, B., & Birkelund, R. (2013). A companionship between strangers - the hospital environment as a chellenge in patient-patient interaction in oncology wards. *Journal of Advanced Nursing*. doi: doi: 10.1111/jan.12204

Leacock, S. (1916). *Essays and literary studies*. Toronto: S.B. Gundy.

Lee, Y.-Y., & Lin, J. (2010). Do patient autonomy preferences matter? Linking patient-centered care to patient-physician relationships and health outcomes. *Socail Science & Medicine, 71*, 1811-1818.

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Newbury Park, CA, USA: SAGE Publications, Inc.

Link, B., & Phelan, J. (2001). Conceptualizing stigma. *Annual Review of Sociology, 27*, 363-385.

Lombard, C. (2014). Coping with anxiety and rebuilding identity: A psychosynthesis approach to culture shock. *Counselling Psychology Quarterly, 27*(2), 174-199.

Loudon, J., Baird, A., Haider, Z., Sein, E., Prabakar, I., & Gebbie, A. (2012). Patients, clients, users or customers: what should we call people attending sexual health services? *Journal of Family Planning and Reproductive Health Care, 38*(1), 19-22.

Luckerhoff, J., & Guillemette, F. (2011). The conflicts between grounded theory requirements and institutional requirements for scientific research. *The Qualitative Report, 16*(2), 396-414.

Macquarie University. (Ed.) (1995) The Macquarie Encyclopedic Dictionary: The National Dictionary. Sydney, Australia: Macquarie Library Pty Ltd.

Manis, J., & Meltzer, B. (1978). *Symbolic interaction: A reader is social psychology* (3rd ed.). Boston: Allyn and Bacon, Inc.

Maoshing Ni. (1995). *The Yellow Emperor's classic of medicine: A new translation of the Neijing Suwen*. Boston: Shambala.

Masters, K. (2008). For what purpose and reason do doctors use the Internet: A systematic review. *International Journal of Medical Informatics, 77*, 4-16.

Mastro, K., Flynn, L., & Preuster, C. (2014). Patient- and family -centered care: A call to action for new knowledge and innovation. *The Journal of Nursing Administration, 44*(9), 446-451.

Mathur, A., Orellana, E., Frohnmayer, A., Jivanjee, P., Nail, L., Hayes-Lattin, B., & Block, R. (2013). Patients' perception of patient-provider communication in fertility preservation decision making among young women with cancer: A qualitative study. *SAGE Open, July-September*. doi: 10.1177/2158244013505293

McCann, T., & Clark, E. (2003). A grounded theory study of the role that nurses play in increasing clients' willingness to access community mental health services. *International Journal of Mental Health Nursing, 12*, 279-287.

McKinlay, J., & Marceau, L. (2002). The end of the golden age of doctoring. *International Journal of Health Services, 32*, 379-416.

McKinstry, C., Hall, S., Hyett, N., & Kenny, A. (2014). *Using digital stories to capture youth perceptions of positive mental health.* Paper presented at the International Journal of Qualitative Methods.

McLaughlin, H. (2009). What's in a name: 'client', 'patient', 'customer', 'consumer', expert by experience', 'service user' - What's next? *British Journal of Social Work, 39*, 1101-1117.

McNaughton Nicholls, C., Mills, L., & Kotecha, M. (2014). Observation. In J. Ritchie, C. Lewis, C. McNaughton Nicholls, & R. Ormston (Eds.), *Qualitative research practice: A guide for social science students and researchers* (2nd ed., pp. 243-268). London, Uk: SAGE Publications Ltd.

Mead, G. (1934). *Mind, self, and society*. Chicago: The University of Chicago Press.

Mead, G. (1936). *Movements of thought in the nineteenth century*. Chicago: Chicago University Press.

Mead, G. (1959). *The philosophy of the present*. La Salle: The Open Court Company.

Mead, N., & Bower, P. (2000). Patient-centredness: a conceptual framework and review of the empirical literature. *Social Science & Medicine, 51*(7), 1087-1110.

Mead, N., Bower, P., & Hann, M. (2002). The impact of general practitioners' patient-centredness on patients' post-consultation satisfaction and enablement. *Social Science & Medicine, 55*(2), 283-299.

Meltzer, B., & Petras, J. (1972). The Chicago and Iowa schools of symbolic interactionism. In J. Manis & B. Meltzer (Eds.), *Symbolic interaction: A reader in social psychology* (2nd ed., pp. 43-57). Boston: Allyn and Bacon, Inc.

Miller, J., & Glassner, B. (2011). The "Inside" and the " Outside": Finding realities in interviews. In D. Silverman (Ed.), *Qualitative Research* (3rd ed., pp. 131-148). Los Angeles: SAGE Publications Ltd.

Mills, J. (2009). The trajectory of cultivating and growing Australian rural nurses: Findings from a constructivist grounded theory study. *Social Theory & Health, 7*(1), 39-54.

Mills, J. (2014). Methodology and methods. In J. Mills & M. Birks (Eds.), *Qualitative methodology: A practical guide* (pp. 31-47). London, UK: SAGE Publications Ltd.

Mills, J., Birks, J., & Hoare, K. (2014). Grounded theory. In J. Mills & M. Birks (Eds.), *Qualitative methodology: A practical guide* (pp. 107-121). London: SAGE Publications Ltd.

Mills, J., Bonner, A., & Francis, K. (2006). The development of constructivist grounded theory. *International Journal of Qualitative Methods, 5*(1), 25-35.

Ming Wen, L., Rissel, C., Baur, L., & Simpson, J. (2011). Who is NOT likely to access the Internet for health information? Findings from first-time mothers in southwest Sydney, Australia. *International Journal of Medical Informatics, 80*(6), 406-411.

Mold, A. (2010). Patient groups and the construction of the patient-consumer in Britain: An historical overview. *Journal of Social Policy, 39*(4), 505-521.

Montgomery, P., & Bailey, P. (2007). Field notes and theoretical memos in grounded theory. *Western Journal of Nursing Research, 29*(1), 65-79.

Moore, J. (2010). Classic grounded theory: a framework for contemporary application. *Nurse Researcher, 14*(4), 41- 48.

Morgan, M. (1982). The doctor-patient relationship. In D. Patrick & G. Scambler (Eds.), *Sociology as applied medicine* (2nd ed., pp. 55-68). London: Balliere Tindall, Elsevier.

Morris, C. (1934). Introduction: George H. Mead as social psychologist and social philosopher. In C. Morris (Ed.), *Mind, Self, and Society* (pp. ix-xxxv). Chicago: The University of Chicage Press.

Morse, J. (2004). Theoretical saturation *Encyclopedia of social science research methods* (pp. 1123-1124). Thousand Oaks, CA: SAGE Publications, Inc.

Mozo-Dutton, L., Simpson, J., & Boot, J. (2012). MS and me: exploring the impact of multiple sclerosis on perceptions of self. *Disability & Rehabilitation, 24*(14), 1208-1217.

Murtagh, M. (2009). Decision-making, power, and the doctor-patient relationship. In A. Edwards & G. Elwyn (Eds.), *Shared decision-making in health care: Achieving evidence-based patient choice* (2nd ed., pp. 79-84). Oxford, UK: Oxford University Press.

National Health and Hospitals Reform Commission. (2009). A Healthier Future for all Australians: Final Report June 2009. Canberra: Australian Government Department of Health & Ageing.

Newman, J. (2000). Beyond the new public management? Modernizing public services. In J. Clarke, S. Gewirtz, & E. McLaughlin (Eds.), *New managerialism new welfare* (pp. 45-61). London: SAGE Publications Ltd. in association with the Open University.

Nielsen-Bohlman, L., Panzer, A., & Kindig, D. (2004). Health literacy: A prescription to end confusion. Washington, D.C: Institute of Medicine of the National Academies.

Nutbeam, D. (2000). Health literacy as a public health goal: A challenge for contemporary health education and communication strategies into the 21st century. *Health Promotion International, 15*(3), 259-267.

Oberg, K. (1960). Cultural shock: Adjustment to new cultural environments. *Practical Anthropology, 7*, 177-182.

Parsons, T. (1951). *The social system*. New York, NY: The Free Press of Glencoe.

Partida, Y. (2012). Language and health care. *Diabetes Spectrum, 25*(1), 19-22.

Patino, A., Pitta, D., & Quinones, R. (2012). Social media's emerging importance in market research. *Journal of Consumer Marketing, 29*(3), 233-237. doi: 10.1108/07363761211221800

Patton, J. R. (2002). *Qualitative research & evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage Publications Inc.

Peirce, C. (1934). *Collected Papers of Charles Sanders Peirce* (Vol. V: Pragmatism and Pragmaticism). Cambridge, USA: Harvard University Press.

Petriwskyj, A., Gibson, A., & Webby, G. (2014). Participation and power in care: Exploring the "client" in client engagement. *Journal of Aging Studies, 31*, 119-131.

Pickstone, J. (2012). Radicalism, neoliberalism and biographical medicine: Constructions of English patient and patient histories around 1980 and now. In C. Timmermann & E. Toon (Eds.), *Cancer patients, cancer pathways: Historical and sociological perspectives*. Hampshire, UK: Palgrave Macmillan.

Pieters, H., & Dornig, K. (2013). Collaboration in grounded theory analysis: Reflections and practical suggestions. *Qualitative Social Work, 12*(2), 200-214.

Pilgrim Projects Limited. (2015). Patient Voices. Retrieved 2 March 2015, from http://www.patientvoices.org.uk/

Pink, S. (2007). *Doing visual ethnography* (2nd ed.). London: Sage Publications.

Plessner, H. (1970). *Laughing and crying: a study of the limits of human behavior*: Northwestern University Press.

Plummer, K. (1996). Symbolic interactionism in the twentieth century: The rise of empirical social theory. In B. S. Turner (Ed.), *The Blackwell Companion to Social Theory* (pp. 223-251). Oxford, U.K.: Blackwell.

Plummer, K. (2000a). Symbolic interactionism and humanism. Retrieved 21 January 2014, from http://kenplummer.com/publications/selected-writings-2/humanism-and-symbolic-interactionism/

Plummer, K. (2000b). A world in the making: Symbolic interactionism in the Twentieth Century. In B. S. Turner (Ed.), *The Blackwell companion to social theory* (2nd ed., pp. 193-222). Massachusetts, USA: Blackwell.

Plummer, K. (2012). My multiple sick bodies: symbolic interactionism, autoethnography and embodiment. Retrieved 21 January 2014, from http://kenplummer.com/2012/07/04/article-my-multiple-sick-bodies/

Prus, R. (2003). Ancient forerunners. In L. T. Reynolds & N. J. Herman-Kinney (Eds.), *Handbook of Symbolic Interactionism* (pp. 19-38). Walnut Creek, CA: AltaMira.

Queensland Government. (2014). Queensland Health: Cairns Hospital. Retrieved 22 September 2014, from http://www.health.qld.gov.au/capeyork/

Queensland Government Statistician's Office. (2014). Queensland regional profiles: Resident profile for Cairns region. Brisbane: Queensland Treasury and Trade.

Quint, J. (1967). *The nurse and the dying patient*. New York: The MacMillan Company.

Ramsden, E. (1980). Values in conflict: Hospital culture shock. *Physical Therapy, 60*, 289-292.

Rapley, T. (2011). Some pragmatics of data analysis. In D. Silverman (Ed.), *Qualitative Research* (3rd ed., pp. 273-290). London, UK: SAGE Publications Ltd.

Ratzan, S., & Parker, R. (2002). Introduction *Current Bibliographies in Medicine 2000-1: Health literacy* Retrieved 9 January 2015, from http://www.nlm.nih.gov/archive//20061214/pubs/cbm/hliteracy.html - 15

Raven, M. (2013). Patient experience of primary health care. Issue 34. *PHCRIS RESEARCH ROUNDup*. Retrieved 1 November 2013

Reeder, L. (1972). The patient-client as a consumer: Some observations on the changing professional-client relationship. *Journal of Health and Social Behaviour, 13*(4), 406-412.

Reichertz, J. (2010). Abduction: The logic of discovery of grounded theory. *Forum: Qualitative Social Research, 11*(1, Art. 13).

Reynolds, L. (2003). Intellectual Precursors. In L. Reynolds & N. Herman-Kinney (Eds.), *Handbook of Symbolic Interactionism* (pp. 39-58). Walnut Creek, CA: AltaMira Press.

Rich, P. (2012). Inside the black box: Revealing the process in applying a grounded theroy analysis. *The Qualitative Report, 17, Article 49,* http://www.nova.edu/ssss/QR/QR17/rich.pdf, 1-23.

Richardson, A. (1994). The health diary: an examination of its use as a data collection method. *Journal of Advanced Nursing, 19*, 782-791.

Richardson, L. (1994). Writing: A method of inquiry. In N. Denzin & Y. Lincoln (Eds.), *The handbook of qualitative research* (1st ed., pp. 516-529). Thousand Oaks, CA: Sage.

Richardson, L., & St. Pierre, E. (2005). Writing: A method of inquiry. In N. Denzin & Y. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed.). Thousand Oaks, CA: Sage Publications, Inc.

Rittenhouse, D., & Shortell, S. (2009). Commentary: The patient-centered medical home. Will it stand the test of health reform? *Journal of the American Medical Association, 301*(19), 2038-2040.

Röing, M., & Holmström, I. (2012). Involving patients in treatment decisions - a delicate balancing act fro Swedish dentists. *Health Expectations, 17,* 500-510. doi: 10.1111/j/1369-7625.2012.00778.x

Rusch, N., Angermeyer, M., & Corrigan, P. (2005). Mental illness stigma: Concepts, consequenes, and initiatives to reduce stigma. *European Psychiatry, 20*, 529-539.

Sandelowski, M. (1998). Writing a good read: Strategies for re-presenting qualitative data. *Research in Nursing & Health, 21*(4), 375-382.

Sandelowski, M. (2000). Combining qualitative and quantitative sampling, data collection, and analysis techniques in mixed-method studies. *Research in Nursing & Health, 23*, 246-255.

Sandstrom, K., Martin, D., & Fine, G. (2001). Symbolic Interactionism at the end of the century. In G. Ritzer & B. Smart (Eds.), *Handbook of social theory* (pp. 217-231). London: SAGE Publications Ltd.

Schatzman, L., & Strauss, A. (1973). *Field research: Strategies for a natural sociology*. Englewood Cliffs, NJ, USA: Prentice-Hall Inc.

Schulz, P., & Nakamoto, K. (2013). Health literacy and patient empowerment in health communication: The importance of separating cojoined twins. *Patient Education and Counseling, 90*, 4-11.

Shibutani, T. (1955). Reference groups as perspectives. *American Journal of Sociology, 60*(6), 562-569.

Shott, S. (1976). Society, self, and mind in moral philosophy: The Scottish moralists as precursors of symbolic interactionism. *Journal of the History of the Behavioural Sciences, 12*, 39-46.

Silverman, D. (2011a). *Interpreting qualitative data*. London, UK: Sage Publications Ltd.

Silverman, D. (2011b). Introducing q*ualitative research*. In D. Silverman (Ed.), *Qualitative research: Issues of theory, method and practice* (3rd ed., pp. 3-12). London, UK: SAGE Publications Ltd.

Simmons, P., Hawley, C., Gale, T., & Sivakumaran, T. (2010). Service user, patient, client user or survivor: describing recipients of mental health services. *The Psychiatrist, 34,* 20-23. doi: 10.1192/pb.109.025247

Sluzki, C. (2000). Patients, clients, consumers: The politics of words. *Families, Systems & Health, 18*(3), 347-352.

Smith, A. (1759). *The theory of moral sentiments*. Oxford: University of Oxford Text Archive.

Sofaer, S., & Firminger, K. (2005). Patient perceptions of the quality of health services. *Annual Review of Public Health, 26*, 513-559.

Spiggle, S. (1994). Analysis and interpretation of qualitative data in consumer research. *Journal fof Consumer Research, 21*(3), 491-503.

Stenhouse, R. (2011). 'They all said you could come and speak to us': patients' expectations and experiences of help on an acute psychiatric inpatient ward. *Journal of Psychiatric & Mental Health Nursing, 18,* 74-80.

Stevenson, F., Barry, C., Britten, N., Barber, N., & Bradley, C. (2000). Doctor-patient communication about drugs: the evidence for shared decision making. *Social Science & Medicine, 50*(829-840).

Stewart, M. (2001). Editorial: Towards a global definition of patient centred care. *BMJ, 322*, 444-445.

Stewart, M., Brown, J., Donner, A., McWhinney, I., Oates, J., Weston, W., & Jordan, J. (2000). The impact of patient-cenered care on outcomes. *The Journal of Family Practice, 49*(9), 796-804.

Strauss, A. (1987). *Qualitative analysis for social scientists*. Cambridge: Cambridge University Press.

Strauss, A. (1993). *Continual permutations of action*. New York: Aldine de Gruyter.

Strauss, A., & Corbin, J. (1990). *Basics of Qualitative Research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.

Strauss, A., & Corbin, J. (1994). Grounded theory methodology: An overview. In N. Denzin & Y. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 273-287). Thousand Oaks, CA, USA: Sage Publications, Inc.

Strauss, A., & Corbin, J. (1998). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* (2nd ed.). Thousand Oaks, California: Sage Publications.

Stryker, S. (1972). Symbolic interaction as an approach to family research. In J. G. Manis & B. N. Meltzer (Eds.), *Symbolic Interactionism: A reader in social psychology* (2nd ed., pp. 435-447). Boston: Allyn and Bacon Inc.

Stryker, S. (1987). The vitalization of symbolic interaction. *Social Psychology Quarterly, 33*(2), 171-198.

Stryker, S. (2008). From Mead to a structural symbolic interactionism and beyond. *The Annual Review of Sociology, 34*, 15-31.

Stubbs, A. (2014). Reducing mental illness stigma in health care students and professionals: a review of the literature. *Australasian Psychiatry, 22*(6), 579-584.

The Beryl Institute. (2015). Home page. Retrieved 13 August 2014, from http://www.theberylinstitute.org/

The National Health and Medical Research Council, the Australian Research Council, & and the Australian Vice-Chancellors' Committee. (2014). *National Statement on Ethical Conduct in Human Research 2007 (Updated March 2014)*. Canberra: Commonwealth of Australia.

Thomas, C. (2013). Medical jargon: Do you need a translator? *Prepared Patient® Blog*. 5 August 2014, from http://www.cfah.org/blog/2013/medical-jargon-do-you-need-a-translator

Thompson, J., Coleman, R., Colwell, B., Freeman, J., Greenfield, D., Holmes, K., . . . Reed, M. (2014). Preparing breast cancer patients for survivorship (PREP) - A pilot study of a patient-centred supportive group visit intervention. *European Journal of Oncology Nursing, 18*, 10-16.

Thornberg, R. (2012). Informed grounded theory. *Scandinavian Journal of Educational Research, 56*(3), 243-259.

Thornberg, R., & Charmaz, K. (2011). Grounded Theory. In S. Lapan, M. Quartaroli, & F. Riemer (Eds.), *Qualitative Research: An Introduction to Methods and Designs*. San Francisco: Jossey-Bass.

Thorne, S., & Darbyshire, P. (2005). Land mines in the field: A modest proposal for improving the craft of qualitative health research. *Qualitative Health Research, 15*(8), 1105-1113.

Tobin, M., Chen, L., & Leathley, C. (2002). Consumer participation in mental services: who wants it and why? *Australian Health Review, 25*(3), 91-100.

Tsai, A., Pierce, C., & Papachristos, A. (2015). From health networks to health: Durkheimafter the turn of the millennium. *Social Science & Medicine, 125*, 1-7.

U.S. Department of Health & Human Services. (2015). Glossary of Terms. from http://effectivehealthcare.ahrq.gov/glossary-of-terms/?filterletter=p

U.S. Department of Health and Human Services. Quick guide to health literacy: Fact sheet. Retrieved 9 January 2015, from http://www.health.gov/communication/literacy/quickguide/factsbasic.htm

U.S. Department of Health and Human Services: Agency for Healthcare Research and Quality. (2014). Background: Patient self-management support programs: An evaluation. from http://www.ahrq.gov/research/findings/final-reports/ptmgmt/background.html

Urquhart, C. (2013). *Grounded theory for qualitative research: A practical guide*. LA: SAGE Publications Ltd.

Van Manen, M. (1989). Pedagogical text as method: Phenomenological research as writing. *Saybrook Review, 7*(2), 23-45.

Walker, D., & Myrick, F. (2006). Grounded theory: an exploration of process and procedure. *Qualitative Health Research, 16*(4), 547-559.

Ward, C., Bochner, S., & Furnham, A. (2001). *The psychology of culture shock* (2nd ed.). London, UK: Routledge.

Weekes, T. (2014). Time to hang up your brushes. *Artist Profile,* 110-111.

Wenzel, M. (2004). A social categorisation approach to distributive justice. *European Review of Social Psychology, 15*(1), 219-257.

Wiener, C. (2007). Making teams work in conducting grounded theory. In A. Bryant & K. Charmaz (Eds.), *The SAGE Handbook of grounded theory* (pp. 293-310). London, UK: SAGE Publications Ltd.

Wirtz, V., Cribb, A., & Barber, N. (2006). Patient-doctor decision-making about treatment within the consultation. A critical analysis of models. *Social Science & Medicine, 62,* 116-124.

Wofford, J., Smith, E., & Miller, D. (2005). The multimedia computer for office-based patient education: a systematic review. *Patient Education and Counseling, 59,* 148-157.

World Health Organization. (2009). Track 2: Health literacy and health behaviour. from http://www.who.int/healthpromotion/conferences/7gchp/track2/en/

Zarcadoolas, C., Pleasant, A., & Greer, D. (2006). *Advancing health literacy: A framework for understanding action*. San Francisco, CA: Jossey-Bass.

Zeng-Treitler, Q., Goryachev, S., Tse, T., Keselman, A., & Boxwala, A. (2008). Estimating onsumer familiarity with health terminology: A context-based approach. *Journal of American Medical Informatics Association, 15*(3), 349-356.

Zhou, Y., Jindal-Snape, D., Topping, K., & Todman, J. (2008). Theoretical models of culture shock and adaptation in international students in higher education. *Studies in higher education, 33*(1), 63-75.