Community-Based Healthcare
PRACTICE, EDUCATION, WORK AND SOCIETY

Volume 12

Series Editor

Joy Higgs AM PFHEA
Charles Sturt University, Australia

Advisory Editorial Board

Della Fish
Chester University, UK
Partner, Education, Practice and Employability Network, Australia

Debbie Horsfall
School of Social Sciences and Psychology
Western Sydney University, Australia
Partner, Education, Practice and Employability Network, Australia

Franziska Trede
Division of Student Learning
Charles Sturt University, Australia
Community-Based Healthcare

The Search for Mindful Dialogues

Edited by

Diane Tasker
Education, Practice and Employability Network, Australia

Joy Higgs
Charles Sturt University, Australia

and

Stephen Loftus
Oakland University, USA

SENSE PUBLISHERS
ROTTERDAM / BOSTON / TAIPEI
# TABLE OF CONTENTS

**Series introduction: Practice, Education, Work and Society** .......................... vii  
*Joy Higgs*

**Preface**......................................................................................................................... ix  
*Diane Tasker, Joy Higgs and Stephen Loftus*

**Section 1: Setting the scene: Community-based healthcare**

1. Community-based healthcare ........................................................................ 3  
   *Stephen Loftus and Diane Tasker*

**Section 2: A qualitative study into community-based therapeutic relationships**

2. Constructing mindful dialogues in healthcare: A phenomenological study .... 11  
   *Diane Tasker and Joy Higgs*

3. Narrative as a lens on practice................................................................. 25  
   *Diane Tasker*

4. Hearing their voices.................................................................................. 33  
   *Diane Tasker*

5. A model for mindful dialogues in community-based practice................... 53  
   *Diane Tasker and Joy Higgs*

**Section 3: Community-based healthcare: Lived experiences**

6. Being a client: It is about me................................................................. 69  
   *Mark Horton and Diane Tasker*

7. Families.................................................................................................... 75  
   *Tania de Bortoli, Diane Tasker and Catherine Murray*

8. When a nurse comes to call................................................................. 81  
   *Helen Fenech, Jackie Finlayson and Diane Tasker*

9. Care and caring: Getting to know you.................................................. 87  
   *Gabrielle Klymenko*

10. A doctor’s tale: “You’re my doc, doc”.................................................. 93  
    *Katriona Herborn*
# TABLE OF CONTENTS

11. Therapy tales: On their turf .......................................................... 99  
*Tania de Bortoli, Bronwyn Couch and Diane Tasker*

12. The care assessor’s story: In the field, from the field ...................... 105  
*Sharyn Williams and Diane Tasker*

13. Life after brain injury: Making a life that works ............................ 111  
*Kathleen McCarthy and Diane Tasker*

14. Mental healthcare in our community ................................................ 117  
*Maria Fitzgerald*

15. Palliative care: Living and dying at home ........................................ 123  
*Debbie Horsfall and Joy Higgs*

16. Case management: Nothing about us without us ............................ 133  
*Jane Meiklejohn*

## Section 4: Ways forward

17. Considerations for quality of life: Always looking from the outside in .... 141  
*Alfred de Leeuw and Chris Atkins*

18. Collaborating in community-based healthcare: Mindsets for relational practice ........................................................................... 149  
*Anne Croker and Diane Tasker*

19. A future path for healthcare in the community: Creating a mindful crucible of healing ................................................................. 157  
*Suzanne Alder*

20. Soul-medicine: An autoethnography ................................................ 167  
*Helen Butlin*

21. Critical companionship: Nurturing mindful dialogues in the midst of practice ................................................................................. 177  
*Angie Titchen and Diane Tasker*

22. Pursuing practice mindfulness and wisdom ...................................... 187  
*Joy Higgs and Diane Tasker*

23. A final word .................................................................................... 197  
*Stephen Loftus and Diane Tasker*

## Contributors

............................................................................................................ 205
This series examines research, theory and practice in the context of university education, professional practice, work and society. The series explores spaces where two or more of these arenas come together. Themes that are explored in the series include: university education of professions, society expectations of professional practice, professional practice workplaces and strategies for investigating each of these areas. There are many challenges facing researchers, educators, practitioners and students in today’s practice worlds. The authors in this series bring a wealth of practice wisdom and experience to examine these issues, share their practice knowledge, report research into strategies that address these challenges, share approaches to working and learning and raise yet more questions. The conversations conducted in the series will contribute to expanding the discourse around the way people encounter and experience practice, education, work and society.

Joy Higgs AM, PhD, PFHEA
Charles Sturt University, Australia
This is a book for practitioners working in community-based healthcare as well as educators of future practitioners and researchers exploring this practice field and for people with chronic disabilities and their families and carers. The book invites readers to re-think and re-shape the way that community-based healthcare is practised by practitioners and experienced/engaged with by clients/patients and their families and other carers. Healthcare occurs within systems and in this case we are talking about the system of community-based healthcare which provides long-term care and support for people with chronic disabilities, and for their families and other carers who participate in the healthcare and support of their family members, friends or clients. The ethos and goals of these systems make a significant difference to the lives of these people. All who are involved in this system (from funders to healthcare providers to support people to clients/patients) need to recognise that both the way the system is constructed and operates as well as the principles and practices it espouses and enacts, are critical to this healthcare; to the experiences, wellbeing and successful care of the clients whose lives can be enhanced or limited by the nature and quality of the care and support they receive and by the role they also play in this process.

This book has left far behind the concept of healthcare as a biomedically-focussed practice with its restitution narrative and it moves beyond a wellness model and narrative with practitioners taking the role of providers of healthcare. Instead, the research underpinning the core healthcare model presented in the book epitomises an approach to healthcare that the authors consider essential to people who – have chronic disabilities, have the desire and capability to write their own life and wellbeing narratives, wish to be co-creators (not just recipients) of their healthcare strategies, are often the owners or inhabitants of the places where their healthcare is conducted and who know more about the realities of their health aspirations and situation than anyone else.

The ideas and research presented in this book are built on an emerging body of work that has identified the importance of context for the practice of home-based healthcare and the need to expand our ideas of knowledge and practice, “beyond the basics” (Heckman & Cott, 2005, p. 280) within this field. Research by Iversen et al. (2008) has highlighted the importance of shared, effortless dialogue and meaning construction and co-construction for therapeutic interaction and Øien et al.’s (2010) research identified the necessity for therapists to be sensitive to and negotiate difficult and dynamic situations to create change and new ways of therapists and patients interacting with each other.

The book has four sections: setting the scene of community-based healthcare, presenting the central research project for the book, lived experiences of participants in community-based healthcare, and ideas about ways forward in this healthcare arena. Authors include the researchers, clients and carers (including a number of participants in the research project) and other workers in this field.

The central research project presented in Section 2 of the book, reveals an embodied style of practitioner-client relationship development perhaps only
possible in people’s homes where the special, local context strongly influences every aspect of the relationship being developed between clients, families and carers. The aspect of private practice within the study added a further dimension that affected relationship development. In the research, six client voices, Eric, Jenny, Jack, Dennis, Adam and Erin (pseudonyms) and their community-based physiotherapists (Karen, John, Lynne and Barbara (pseudonyms) speak out strongly in conversation with Diane (Tasker) the principal researcher. Each of these participants brought their long-term experience (as people with disabilities, family members, carers and as practitioners) to enrich our understanding of this complex, challenging and rewarding field of practice.

In Section 3, narrative chapters have been written in company with a wide range of practitioners and stakeholders. These stories from practice from the perspectives of different practitioners and stakeholders in community-based healthcare are lightly inspired by Geoffrey Chaucer’s late 14th century Canterbury Tales, where a traveller talks to other travellers to hear their tales and better understand them. The intent of writing these chapters in company with practitioners from many different disciplines and levels of experience can be seen as phenomenological in nature - like the Mindful Dialogues study itself, where the interviewer wanders along with the local inhabitants, asks questions that lead the subjects to tell their own stories of their lived world, and converses with them in the original Latin meaning of conversation as “wandering together with” (Kvale, 1996, p. 4). The chapters in Section 3 also encourage dialogue between the authors to explore what they consider to be important issues in community-based healthcare and the relationships that develop therein.

In Section 4, authors have contributed discussion and application of central themes and ideas to the field of community-based healthcare in an effort to think forward for and with the people involved in community-based healthcare. The authors involved have long experience as both practitioners and academics; their visioning and thinking can assist development of practice in this field.

We invite readers to reflect on their practice, their lives, and their current and possible ways of being, knowing, doing and becoming in this space of living, practising and co-creating life possibilities. This is a book to dip and delve into; to read and reflect upon. We encourage you to make time for thought and goodwill in your busy lives and engage in dialogue with others.

Diane Tasker, Joy Higgs and Stephen Loftus

REFERENCES


SECTION 1

SETTING THE SCENE:
COMMUNITY-BASED
HEALTHCARE
1. COMMUNITY-BASED HEALTHCARE

In recent years community-based healthcare has started becoming more important. This is because hospital stays are becoming much shorter. Clients are being discharged from hospital into community care much earlier than they were in the recent past. As our ability to deal with acute conditions, such as the trauma from road accidents improves, more people are surviving with impairments which need continuing care, usually provided in the community. In addition to this, an aging population means there has been a steady rise for some years in the number of people with chronic conditions who live in the community and are cared for in that same community (commonly referred to as “aging in place”). As the baby boomer generation moves into old age, the number of older people being cared for in their community is expected to rise dramatically. There is a pressing need to have a better understanding of community-based healthcare in its full complexity. In this chapter we draw attention to some of the factors that contribute towards that complexity and how health professionals can engage more fully with community-based healthcare.

Conventional ways of viewing healthcare leave much to be desired as they are dominated by the discursive lenses of managerialism and competency-based practice. These discourses have a limited vision and vocabulary. If we rely exclusively on these approaches then much of the complexity of community-based healthcare will go unnoticed and be poorly understood. Managerialism and competency-based healthcare have a focus on the short term and the superficial. This is seen in simplistic attempts to “deliver” so-called “packages of care” quickly and efficiently and at the lowest cost. There is an underlying assumption that healthcare can be packaged up and so delivered. While this may often be true in the acute setting, long-term community care needs a different kind of thinking and relies on different assumptions. Relationships develop between health professionals and clients (and their families) where long-term care is provided in the home on a regular basis. Acute care thinking sheds no light on the nuances and subtleties of the relationships that develop in more long-term community-based care. We argue that ideas from such disciplines as narrative medicine, neo-Aristotelianism and dialogism are particularly useful in helping us understand the complexity of community-based healthcare. If we are to provide this care in a manner that truly helps people (and is effective and efficient at the same time) then we need to engage with this complexity.
Recent research has started to open up the complexity of community-based care settings (Tasker, 2013). A clinical encounter in these settings is often one in a long series of encounters that can go on for months or even years. This means that there is time for the participants to get to know each other well and develop complex relationships that evolve over time. The relationships are not only between the health professional (e.g. a physiotherapist) and the client (sometimes called client) but also between the health professional and the families who provide the ongoing care when the health professional is not physically present. Health professionals, therefore, need to be sensitive to how such relationships can develop and do what they can to ensure that these relationships remain healthy in order to provide a setting where all concerned can benefit. Health professionals must, therefore, find a balance between being friendly and supportive on one hand and maintaining a professional distance on the other where they can fully exercise their specialised skills and knowledge. Most health professionals tend to learn their specialised skills and knowledge in clinics and acute hospital settings, which are designed so that health professionals can be as efficient and effective as possible. In these settings, initiative and power rest with the health professionals who are in familiar surroundings with all the paraphernalia that goes along with their profession. In community settings clinical encounters often take place in a client’s home where clients and families are on familiar territory where they can take some initiative and can expect some power sharing. All this can affect how professional relationships develop. In hospitals, health professionals hold nearly all the power. In people’s homes the balance of power is a little more even.

One common example is that of a physiotherapist who makes visits to a client in their own home. It has been pointed out that in these settings the physiotherapist is entering a “sacred space” (Tasker, 2013, p. 170) when therapy moves into the family’s space. Health professionals need to be very mindful of this dynamic if they are to be able to respect people’s rights to privacy and autonomy within their own home and this dynamic extends to respecting the body of the client as well. Clients and families usually want to decide what is important to them as a family as well as what is important to the person directly receiving the healthcare. Health professionals and support workers from different disciplines are also involved and so the breadth and complexity of healthcare support in the community builds. There are a number of theoretical frameworks that can be used to help us conceptualise such complexity and we discuss some of these next.

DIALOGISM

One theory that has much potential to help us understand the complexity of community-based healthcare is dialogism. This is based largely upon the work of the Russian scholar, Mikhail Bakhtin (1981, 1986, 1984, 1990), whose work has started to influence many disciplines since it came to the attention of the western world towards the end of the twentieth century. In dialogism, dialogue provides a
metaphor for comprehending meaning. In dialogism it is assumed that all meaning arises from relationships, whether this is someone reading a text, or two people in conversation within a clinical encounter. There is no inherent meaning in the text or in the individuals but meaning arises when these entities relate to each other. Hence, my reading of a text will necessarily generate different meanings from your reading of the same text because we come from different backgrounds and establish different relationships with that text. The same applies to human relationships. The implication for healthcare is that every clinical encounter is necessarily different from every other even though they may follow much the same pattern. There will be subtle differences between the meanings generated with one physiotherapist and a client compared to the meanings generated with another physiotherapist even though they may be trying to deliver the same therapy to the same client.

In a study of physiotherapeutic relationships in community-based healthcare (Tasker, 2013), the family of “Jack” (not his real name), a young man with acquired brain injury told of the way he and the family related to his therapist at home compared to the therapist who had helped him in the hospital prior to his return home. While the context within which those therapies had taken place had obviously affected the way this young client perceived and responded to his therapy, the different people involved also affected his reaction to the different therapists and the meaning he gained from their interaction together. His father told of the development of this home-based therapeutic relationship where he had gradually gained insight into his son’s need to be independent in his own way after listening to the quite experienced community physiotherapist as she worked with Jack and all the family in their home. The aims of the basic physical therapy being conducted in hospital and at home may have been quite similar but the way the therapeutic relationship between these people played out had particular and different meanings for Jack and his family. We need to be keenly sensitive to such subtle differences in meaning if we are to be able to connect with our clients in ways which can help them.

Another aspect of dialogism is the acceptance of multiple voices and the autonomy of those involved in relationships. Bakhtin pointed out that the novelist, Dostoyevsky, took pains to avoid a god-like relationship with the characters in his novels. It was as if Dostoyevsky gave his characters the autonomy to be themselves. How does this apply to healthcare? The traditional view of the clinical encounter is that the health professional’s voice is dominant and is the only voice with any power. Clients and their families are traditionally expected to do what they are told. In a more dialogical approach it is accepted that all participants have a voice and a viewpoint that needs to be taken into account, even though the health professional is recognised as having specialised knowledge and expertise. Therapeutic plans need to be negotiated with clients and families in a manner that allows everyone concerned to feel they have made a valid contribution and have been heard. There is dialogue of all participants rather a monologue from the health professional. A dialogical approach also allows the voices of other disciplines to
inform what we can understand of the clinical encounter. One other such discipline is narrative inquiry.

**NARRATIVE**

The study of narrative encourages us to pay attention to the ongoing stories that clients and their families are living out. The community-based healthcare needs to become part of the client’s narrative and all concerned need to be involved in this. Mattingly (1994) showed the usefulness of adopting a narrative approach to rehabilitation therapy. In her case, the clients were young men permanently disabled by trauma, frequently motorbike accidents, who were having to make adjustments to a new life living with impairment. The exercises and routines were presented as part of the new life story that the clients were invited to develop for themselves. The narrative approach gave meaning and direction to the therapy provided. The new life story of a fulfilling life that included coping with impairment was seen as the overall goal of therapy. With a meaningful goal, there was incentive to learn how to overcome and cope with a disability and move on with life, even if that life now had to be radically different.

In community-based healthcare there is the same need for narrative sensitivity. Many of these clients may be entering their final years and are expected to decline. Their narrative possibilities may be limited but they are still living out their life stories and therapists need to be sensitive to these stories and the role community-based healthcare can play within them. To add to the complexity there is a need to be sensitive to the ways in which the life stories of clients may be interacting with the life stories of the family members who do the caring.

Recognition and understanding of what people are trying to communicate about the meanings in their relationships with their health professionals was facilitated in a research study through the use of such skills as poetic recognition of the language and phrases used by clients (Tasker, Loftus, & Higgs, 2014). This has implications for professional practice as well. Such sensitivity on the part of a healthcare professional can also be described in terms of phronesis.

**PHRONESIS**

Phronesis has been described as practical wisdom or the disposition to act wisely (Aristotle, 2012). It comes from neo-Aristotelianism where it is contrasted with *episteme*, propositional knowledge, or knowing that, and *techne*, technical procedural knowledge or knowing how. Phronesis is the ability to deal with the uncertainty, complexity, value conflicts and uniqueness of practice situations. Community-based healthcare is often full of such situations. Practitioners who are going to become involved in these settings need to develop a deep sense of phronesis and accept that the complex relationships and demands made upon them mean they will need to accept complexity and uncertainty as part and parcel of community-based healthcare.
Situational complexity can involve potential value conflicts, such as finding a balance between providing high quality care and cost-effective care. The complexity may involve helping clients and family members to negotiate life stories that are mutually acceptable. For example, clients may worry about being a burden to their families and resist home care while those same families may want home care provided. Conversely, while some clients may want to live out their days at home, and die surrounded by family in familiar surroundings, family members may feel that home care is too much of a burden and be overwhelmed with the responsibility and the adjustments needed in their own lives. There is no single right way that can be imposed on everyone involved. Every case will be different and needs to be managed carefully. Health professionals may need to help clients and family members to articulate their desires and expectations so that there is the possibility that meaningful life stories can be negotiated for all concerned.

All this means that practitioners need to be able to engage in reflective practice, both reflection-in-action and reflection-on-action (Schön, 1983, 1987). Reflective practice opens up the possibility of developing practice wisdom. Practice wisdom depends on the abilities of practitioners to reflect upon and learn from their experiences. The experiences, where complexities such as value conflicts or ambiguity can prevent decisions and management from being straightforward, are the very experiences that demand reflection. Practitioners can find themselves asking difficult questions that have no easy answers. What exactly is going on here? What options are possible? How does my behaviour/relationship need to be modified in order to bring about the best possible outcome for everyone? What compromises have to be made and who is going to make them? Whose interests are being served by each decision option? What is the ethical thing to do here? Do I need to bring in someone else? In order to answer these questions practitioners need to develop the phronesis mentioned earlier, the disposition to act wisely. This phronesis cannot be taught but junior practitioners can be given the chance to develop it by working in practice settings where they have the chance to encounter some of the difficulties mentioned. They also need to work with more experienced practitioners who can role model how to cope with complexity and who can mentor the juniors as they jointly reflect on the problems thrown up in practice and how to cope with them (see chapter on Mindful practice in Section 4). This practice-based approach to education fosters the development of what has been called praxis.

Praxis has been defined as morally informed and morally committed action (Kemmis & Smith, 2008). It is a form of practice that is deeply ethical where there is a conscious effort to bring about the best outcome for all concerned, especially clients, recognising that the best outcome can vary depending on subtle changes in context. An example of such praxis can be seen in community health situations where considerations of safety must be weighed with “dignity of risk”, especially for people with cognitive impairment, who are living alone in the community and who wish to remain doing so. Advocacy for these people must be tempered with both communication and education of those around them and careful ongoing interaction if the needs, wishes and fears of all concerned are to be fully taken into
account and the client to be safe in what they wish to do. Indeed, the health professional’s access to the situation may well also depend on the ability to adequately manage such complex situations. The *Mindful Dialogues* model (Tasker, 2013) of being mindful, staying engaged and being responsive is of utmost importance in such professional praxis (see Section 2).

**CONCLUSION**

It is clear that community-based healthcare can be extremely complex in ways not seen in acute care settings. There are nuances and subtleties that are simply not present in clinics and hospitals where most clinicians learn their professions. While clinics and hospitals have their own complexities the nature of these can be quite different. Therefore, those who engage in community-based healthcare need to be made aware of the particular complexities they face and be prepared to engage with them. The rest of this book explores some of these complexities in more detail.

**REFERENCES**


Stephen Loftus PhD
Oakland University William Beaumont School of Medicine, Rochester, MI, USA

Diane Tasker PhD
Education, Practice and Employability Network, Australia
SECTION 2

A QUALITATIVE STUDY INTO COMMUNITY-BASED THERAPEUTIC RELATIONSHIPS
2. CONSTRUCTING MINDFUL DIALOGUES IN HEALTHCARE

A Phenomenological Study

The curiosity that inspires qualitative research often comes initially from observations of the real world, emerging from the interplay of direct experience with emerging theory, of political commitment with practice, as well as from growing scholarly interests. (Marshall & Rossman, 1999, p. 25)

THE ORIGINS OF THIS RESEARCH

This research arose from four key points of reflections and concerns:

- the imbalance between the need for community-based healthcare in the context of aging populations and the limited attention given to such programs in healthcare systems
- the concern that a different approach was needed for chronic healthcare in which different practitioner-client relationships were essential
- the need for greater recognition of the role of clients and families in community-based healthcare, particularly where their homes become the venue for healthcare
- the experience of the principal researcher (Tasker) in addressing these concerns.

Community-Based Healthcare and the Need for Better Attention

Throughout the ages, people have always been cared for at home when they have become ill or disabled. However, in Western society, the introduction of hospitals and the hegemony of specialist medical practices over the last century may have affected the place of community-based healthcare within healthcare systems. The development of community-based healthcare as an add-on to hospital-based healthcare (Lechner & Neal, 1999) may have occurred as a result of a lack of interest in chronic and complex healthcare by specialists who have historically focused on acute conditions, where there is a greater possibility of substantive cure (Bishop & Scudder, 1990). However, as the economic burden of healthcare for our increasingly aging population becomes more pressing, public interest has again turned to community-
based options. Such options can save money but also have the potential to promote an enhanced quality of life for individuals with chronic health conditions, providing home-based care to transition clients into improved health, rehabilitation, or as ways of coping with chronic conditions.

**Finding a Different Approach to Community-Based Healthcare**

Assisting people with healthcare needs who wish to remain in their own homes is a desirable outcome for many people. As our society ages, discourse regarding the care of people with disability becomes more important and more urgent. It is dominated by concern from community members regarding the quality of care achievable by healthcare organisations, for example, hospitals and nursing homes. Increased understanding of the therapeutic support required in community-based healthcare settings may contribute some resolution to the increasing problems of our aging society and its healthcare needs. In community-based physiotherapy, such therapeutic support can be centred within the relationships, which develop between physiotherapists, clients, families and carers.

**Recognising Client and Family Needs and Roles in Community-Based Healthcare**

In informal discussions with colleagues from general medical practice and other healthcare professions regarding this research, wholehearted belief was expressed that community-based healthcare essentially depends on therapeutic relationships with clients, their families and carers. In a world that values accountability for economic reasons as well as desirable healthcare outcomes, this project tried to illuminate the human relationships experienced by community-based therapists and their clients.

This research contributes deeper understanding and new meaning to the discourse regarding the provision of customised therapeutic support for people living at home with chronic and complex healthcare needs. Within this study, the contributions from all the stakeholder participants in community-based physiotherapy situations demonstrates the way that all people within such situations contribute to person-centred healthcare processes.

**Being a Different Kind of Community Health Carer**

Professional healthcare practice is not only about “doing” but also about “being” and the formation of one’s professional persona is a delicate balancing act for all healthcare professionals. Through her 25 years of community-based physiotherapy practice of the principal researcher, first author, Diane became increasingly aware of the complexity and fragility of the human relationships, which develop between physiotherapists, clients, their families and carers. She noted particularly that a deeper, unhurried and more socially sensitive, interactive approach supported the development of wellness for her clients and their families and sustained her energy as a therapist and as a person. She recalls one client for whom it was her emotional...
support for the person, not any physical therapy that made an enormous difference to a physical state that had become a disability for over two years.

As a physiotherapist, I often wonder just how much I have contributed to a client’s progress. Is it what I did or how I did it, or what they thought and did, or something in the interaction between us? There are times in clinical practice when I have to stop and really question myself about this. Some time ago, I visited an elderly man with back and hip pain. He was bent right over. His doctor told me that this flexed body posture has been present for at least 2 years that he could recall. This client also had very poor vision. He had quite a prickly personality but gradually our conversation progressed.

I asked him about his life in general and he told me with some distress that he couldn’t believe that this had happened to him, and that in his youth, he had been a very good athlete. He got out a photo album and showed me a picture of himself as a teenager. I admired his beautiful upright posture in the photos and asked him if he could remember what that had felt like. We chatted about how he managed his mobility and arranged some appointments and a plan of action. I also assessed him physically and suggested that he use his walking frame in the house instead of just on outings.

Imagine my surprise when I visited the next week. He greeted me at the door with a big smile, standing nearly upright without his walker. To say that I was surprised is an understatement. What I was sure of was that it was not any evidence-based physiotherapy procedures that had wrought this change.

Diane became increasingly fascinated by the role and importance that such human relationships could play within clinical practice and how attention to interpersonal interaction could help clients, families and practitioners in their effort to achieve wellness and good health outcomes. This interest led her to enrol in a doctoral program to research the community-based physiotherapy relationships that develop between community-based physiotherapists, their clients, clients’ families and clients’ carers.

THE CONTEXT OF THE RESEARCH: COMMUNITY-BASED PHYSIOTHERAPY

Although physiotherapy as a profession was established only within the last 100 years, it has been developing against a background of great change within society (including two world wars, globalisation, and changing attitudes and costs associated with health and wellbeing). Key factors in Australian healthcare include the combined impact of an aging population, the increased incidence of chronic conditions such as diabetes and cardiovascular disease, and increased disability rates linked to improved survival rates following serious injury. Many more people are living longer with significant disabilities, requiring an expansion of long-term care and community-based care. It is within these changing contexts, that the concept of physiotherapeutic relationships in the care of people with chronic ill
health was examined, using research and knowledge from other disciplines as well as physiotherapy to gain further insights.

In Australia, the State Health Department in Victoria commenced physiotherapy home visiting in 1947 after the Australian poliomyelitis epidemic but the presence of physiotherapists based in community-care centres and able to do home visits, did not generally occur until the 1970s (Park, 1972). Park (1972) reported that general rehabilitative care was usually undertaken by district nurses until, following work in Canada where physiotherapists were placed with district nursing services to carry out education of district nurses, similar efforts were made in Australia.

There are strong elements of this consultative role still present within physiotherapists’ work in community-based healthcare today, with an increasing emphasis on community access, continuity of care and integration of services, rather than hands-on treatment (Struber, 2003). This emphasis on education and consultancy by physiotherapists can also be related to the influence of the WHO (World Health Organization) on physiotherapy practice roles.

In 1996, Australia developed National Health Priority Areas in response to the WHO global strategy on health reform (Australian Institute of Health and Welfare, 2011). The WHO global strategy was planned with the aim of decreasing the burden of chronic disease for world communities. This aim was further reinforced with the WHO follow-up report, *People at the centre of health care: Harmonizing mind and body, people and systems* (WHO, 2007).

Awareness of the concepts of “self” and “other” have developed thinking about the way we exist in the world and depend upon each other for the creation of human relationships. Such discourse opened up acceptance of individual concerns as having legitimacy within the community and between people. Accordingly, for the purposes of this project, the term community-based physiotherapy and healthcare was defined as physiotherapy and healthcare provided to clients within the environment where they “learn, work, play and love” (United Nations, 1986, p. 2). This upholds the spirit of the advice expressed in the Ottawa Charter for Health Promotion:

> Health is created and lived by people within the settings of their everyday life; where they learn, work, play and love. Health is created by caring for oneself and others, by being able to take decisions and have control over one’s life circumstances, and by ensuring that the society one lives in creates conditions that allow the attainment of health by all its members. (United Nations, 1986, p. 2)

**ESTABLISHING THE LENSES FOR THIS RESEARCH**

Just as research occurs within a socio-cultural, historical and physical context, it also occurs within the frame of reference of the researchers. To each project, researchers bring their interests, values, previous knowledge and experience and their pre-knowings. In this research the principal researcher (Diane Tasker, doing her doctoral research) and her supervisors (Stephen Loftus and Joy Higgs) brought their
insights and recommendations to this choice of research interpretation lenses. In summary, the interpretive lenses were used first, to create a series of foci to select the key elements of the complex arena and phenomenon of community-based healthcare relationships, upon which, the research would concentrate.

- **Practice models and professional judgement:** Within the development of the profession of physiotherapy, it is not surprising that dominant views should mirror the dominant discourses present in general healthcare, medicine and society. In shaping their practice, health professionals are often confronted with the problem of how to deal with expectations of the evidence-based practice era. Tension between the way health professionals project their image when communicating with clients and the way they might be feeling about those interactions can be influenced by the introduction and development of evidence-based medicine.

Since the early 1990s, evidence-based practice and its principles have been increasingly discussed and promoted within the physiotherapy literature (Schreiber & Stern, 2005). Within this context of system expectations and dominant practices, health practitioners, as professionals, need to make decisions about what values and models of practice they wish to enact and be held accountable for through their practice. Professional judgement is a core ingredient of practice models and determines how practitioners shape their practice and practice interactions.

- **Capabilities and practice-based knowledge:** Within community-based physiotherapy practice, where physiotherapists are “guests”, there is a particular need for “a broad array of knowledge and skills far beyond traditional notions of physiotherapy” (Heckman & Cott, 2005, p. 278). From Di’s personal experience and communications with fellow therapists, she noted that higher value can be ascribed to learning from the literature, training courses and other professionals, despite any personal misgivings practitioners might have or the possibility of alternative approaches they might have discovered through actual practice.

Actual practice includes a gradual and subjective building of craft knowledge, involving interpretation in context, in contrast with the more objective and generalised nature of evidenced-based knowledge (Higgs, Richardson, & Abrandt Dahlgren, 2004). Shaw and DeForge (2012), have argued for a similar approach to understanding how physiotherapists might view their practice, emphasising that “claims to expertise always consist of partial knowledge claims that emphasize different elements of physiotherapy practice” (p. 427) and that physiotherapists must be better viewed as “bricoleurs”, embracing knowledge from a variety of partial perspectives. Acknowledgement of the evolving and incomplete nature of knowledge could encourage physiotherapists to draw from those bodies of knowledge that are undervalued and marginalised, using philosophical and theoretical insights to explore new and varied ways to approach physiotherapy practice. An ability to draw on more marginalised knowledge can arguably enrich practice.
Chosen approaches of wellbeing and flourishing: Chronic and complex healthcare is, as its name suggests, ongoing and difficult to manage, for all stakeholders and healthcare systems generally struggle to address such complex issues (Ginter, Swayne, & Walter, 2002). Healthcare research often focuses on acute and tertiary healthcare rather than chronic/rehabilitation and low-tech community healthcare. This research was located in spaces that evidence-based practice tends to sideline; dealing with clients’ experiences, choices and feelings. It emphasised the importance of individual subjectivity rather than generalised approaches to treatment based on quantitative evidence, and it promoted the judgement of the professional as well as the use of standardised evidence in the co-creation of particularised care.

The biomedical illness and cure model frequently dominates healthcare, particularly in acute care situations. It is rarely the complete or even preferable narrative in chronic healthcare for people with disabilities. The desired effect of “wellbeing” or “flourishing” is identifiable to and experienced (often differently) by family, carers, therapists and clients. Such wellbeing transcends the physical and involves personal and interpersonal aspects of health and healthcare.

Clients and their carers will be able, in varying degrees, to take part in therapeutic exchanges and use them to promote their own wellbeing. Some clients and/or the family/carers may wish to and be capable of leading their own healthcare within their home. Community physiotherapists will need to be able to assess this desire/ability and respond appropriately, to balance both the client’s wishes and their best interests therapeutically. Long-term clients and their carers have a wealth of experience and insight; they are vital creators of their own wellness narratives.

Relationships: All branches of healthcare have gradually recognised the importance of interpersonal connections between clinicians and their clients. The term “therapeutic relationship” within such approaches is often used within the areas of psychology, nursing and occupational therapy, but within physiotherapy the literature more often uses terms such as therapist/patient or patient/therapist relationships (French & Sim, 2004). Such a dry and clinical way of describing human relationships (in healthcare) does not do justice to their complexity. Accordingly, for the purposes of this research project, the term, therapeutic relationship was defined as “a trusting connection and rapport established between therapist and client through collaboration, communication, therapist empathy and mutual understanding and respect” (Coles & McLean, 2003, p. 33). Concern for “the self” of the client serves to place emphasis on interpersonal relationships and their potential, rather than just on clients’ biomedical conditions, clients/ bodies or practitioners’ viewpoints.
Relationships between clients, families, carers and therapists are inherently complex. This is often linked to such factors as personalities, family history, challenges in dealing with chronic illnesses and the situations (e.g. working in home/personal spaces) where community physiotherapy occurs. A deeper understanding of how such professional relationships can develop might help therapists to craft successful engagement strategies and outcomes for clients and their families/careers. Physiotherapists explore/teach/model therapy tenets to clients and carers/families via their relationships with those people. Attention paid to this tacit and under-acknowledged aspect of physiotherapy practice could improve the ability of both new and working therapists to enhance their professional practice for both their clients and themselves.

Second, three theoretical lenses were used to interpret ways that the researchers as well as the participants in the phenomenon of community-based healthcare could make sense of the healthcare situation, interactions and experiences and these same elements within the research findings. The latter was pursued through the ideas of narratives (storytelling of experiences past and envisaged), and realising the way that people often communicate their life experiences through storytelling.

**Social constructionism: the processes of making meaning between people**

The social constructionism movement studies processes of making meaning, which occur between people as they seek to communicate with each other and establish interpersonal relationships. In particular, proponents seek to understand the conventions of language and the social processes that are used by people within human interaction. Social constructionism proposes that knowledge is not merely individually generated but also created collectively as a result of the fluid, relative and subjective nature of our interpersonal processes (Schwandt, 2003).

Social constructionism was used to inform this research because it focuses attention away from both study of individual people and the study of the external world, and towards the study of human inter-subjectivity and interaction. The methodology of hermeneutic phenomenology, chosen for this research project (see below), required iterative focusing and distancing of viewpoints to gain a holistic but deeply textured understanding of the research phenomenon. Social constructionism provides insights aligning well with this methodology.

Drawing from the field of psychology, the strategy of communicative interaction can be seen as occurring within communicative space (Shotter, 1999, 2008). This strategy allowed the research to examine conversations that occur in this space, and also how these conversations might contribute, in this case, to the way physiotherapists practise relational healthcare, for and with clients, families and carers. This fits with the argument that practitioners working in the space of community-based healthcare need to embody a new relational practice, to change what they notice and are sensitive to (as well as what they care about, and feel are appropriate goals to pursue).
Thus, we need to change ourselves, our sensibilities, the “background practices” we have embodied that make us the kind of professionals we want to become (Shotter, 1998, p. 35). One of the concerns of social constructionist thinking is to highlight different aspects of the background to our everyday life and to examine how those aspects might relate to particular human phenomena of interest (Shotter, 2008).

-- Narrative and the importance of interpersonal connection in healthcare
The concept of narrative recognises the storied nature of human relationships in general and clinical practice (and physiotherapeutic relationships in particular). Narratives provide us with master plots that help us to understand the usual sequence of events in relationships and how we are expected to proceed. A master plot, or story outline, has a temporal nature that can also help us understand the process of a developing relationship between people. While not employed as a major or overarching methodological strategy, the use of narratives was chosen as a powerful theoretical lens to inform this project. For this project, the work of scholars such as Arthur Frank (1995, 2002, 2004), from a background of English, psychology and sociology, and Cheryl Mattingly (1998), from a background in occupational therapy and anthropology, helped to combine views from different disciplines, offering a rich and multi-faceted opportunity to study the phenomenon of clinical relationships and reveal new knowledge about community-based physiotherapy practice. Understanding the development of clinical relationships in which participants are of various ages, cultures and personalities can be challenging but use of narrative can allow fusion of ideas between people of different backgrounds. The use of narratives within this research study is explored more fully in Chapters 3 and 4.

The chapters in Section 3 have also used stories from practice from the perspectives of different practitioners and stakeholders in community-based healthcare, lightly inspired by Geoffrey Chaucer’s late 14th century Canterbury Tales, where a traveller talks to other travellers to hear their tales and better understand them. The intent of writing these chapters in company with practitioners from many different disciplines and levels of experience can be seen as phenomenological in nature - like the Mindful Dialogues study itself, where the interviewer wanders along with the local inhabitants, asks questions that lead the subjects to tell their own stories of their lived world, and converses with them in the original Latin meaning of conversation as “wandering together with” (Kvale, 1996, p. 4). The chapters in Section 3 also encourage dialogue between the authors to explore what they consider to be important issues in community-based healthcare and the relationships that develop therein.

-- Social poetics
Poetry often has the capacity to penetrate experience more deeply than prose (Furman, 2006). Social poetics involves the use of metaphor and other figures of speech occurring in ordinary speech and prose. Analysing the expressions of research participants with insights from poetics helps researchers enter the
complex lifeworld of participants. Appreciation of poetics helps researchers to be more sensitive to the deeply personal aspects of participants’ stories. Participants’ expressions are used to focus attention on relations between aspects of our human activities, which can go unnoticed in the everyday, busy-ness of our lives (Shotter, 1997).

Recognition and use of poetic language forms locates an essential way of being within participants’ socially constructed viewpoints, allowing us to connect with their experience. The use of poetics within the data analysis and presentation of findings in this project allowed access to unexpected and hidden thoughts, feelings and meanings from a particular participant’s point of view. By observing and highlighting the poetics of everyday speech within human interaction, researchers create rather than discover new understandings of human experience and interaction (Aldridge & Stevenson, 2001). Use of the poetic in research encourages an open attitude in readers towards the reality of another person’s experience, engendering empathy and acknowledgement of the different ways that others experience reality.

Poetics were used for different purposes within this research. Prior to and throughout the research process, pieces of free verse were written to allow reflection and a layering and deepening of understanding. During data analysis, poetic phrases “found” within the data provided meaning markers acting to promote understanding between researcher and participants. Appreciation of the poetic in the data assisted the presentation of findings via the use of “derived” poetry and also suggested points of entry for further consideration of certain issues. The use of poetics in this study enabled the phenomenon of interest to move from the local, specific and particular context of community-based physiotherapy towards wider issues of societal concern.

Finally, we looked at the way that people reading the research could best experience and “get in touch with” the research phenomenon the research was seeking to illuminate and the choice was made to engage the reader through poetics and narratives constructed from the research findings. These research communications and artefacts are discussed further in Chapter 4.

SHAPING THE RESEARCH QUESTIONS

The research was built on the argument that relational community-based physiotherapy practice occurs in situated, person-centred, therapeutic relationships, which enable clients and carers to co-construct their therapy programs and shape their healthcare journeys. The research therefore aimed to illuminate aspects of human relationships within such practice to explore how community-based physiotherapists developed reciprocity within those relationships with clients and their families and carers.
The research questions explored the participants’ thoughts and feelings about their community-based physiotherapeutic relationships in order to reveal benefits for other people in similar healthcare situations:

1. How do community-based physiotherapists experience and foster relationship-centred care within the dynamic and ongoing therapeutic relationships they develop with clients, their families and carers?

2. How do clients, their families and carers, experience and understand their ongoing relationships with community-based physiotherapists?

BASING THE RESEARCH WITHIN THE INTERPRETIVE RESEARCH PARADIGM

This qualitative research was conducted within the interpretive research paradigm and was focused on people involved in real-world activities and relationships, increasing the visibility of that world (qua Denzin & Lincoln, 2000). Such research typically deals with lived human experience. In contrast to quantitative research, which offers an interpretation of a material world that cannot interpret itself (Mattingly, 1993), qualitative research develops interpretations of an already interpreted human world. If we accept the philosophical argument that humans are essentially self-interpreting beings (Heidegger, 1962), it becomes necessary to acknowledge each participant’s views of, and contributions towards the lived phenomenon in question, in this case the healthcare situations in which they find themselves. People need to manage many serious healthcare problems by themselves. A qualitative approach to research and knowledge allows engagement with their efforts and trials.

Through “listening and talking together” with the participants in healthcare the researchers were able to reveal the tacit dimensions of the relational processes that make up community-based physiotherapeutic relationships. Researchers can better develop new knowledge for the future if they acknowledge the experience and pre-existing knowledge of the human beings participating in their research. It is not enough just to theorise from a practitioner’s point of view, we must also listen to what they and we have to say.

HERMENEUTIC PHENOMENOLOGY AS A RESEARCH APPROACH

Within this research project, participants were encouraged to tell stories about their physiotherapeutic relationships to reveal how the meaning of those relationships was managed. Phenomenology involves the study of human experience as it is lived by people (van Manen, 1990). Such studies aim to access the essence of that experience by examining the talk or writings of people from where they are located within their own perceived worlds. The complexity of human experience is then “thickly described” (Ryle, 1949, 1971) in an effort to properly consider the depth and intricacies of that essential experience.

Within the interpretive paradigm and from the range of phenomenological approaches available, a hermeneutic phenomenological approach was adopted to
CONSTRUCTING MINDFUL DIALOGUES

richly explore the lived experience of clients with chronic and complex healthcare needs, and the related experiences of their carers and families. Hermeneutic phenomenology allows the iterative and embodied study of lived experience, such that the findings are co-created between participants and researcher (Spence, 2001).

RESEARCH PARTICIPANTS

People caring for relatives with chronic and complex healthcare needs at home depend on their communication with healthcare professionals for support of their quite prodigious efforts. This research focused on experiences and thoughts regarding development of community-based physiotherapeutic relationships, as interpreted by clients living at home, with chronic and complex healthcare problems, families of those clients, carers for those clients and physiotherapists attending those clients. The roles and contributions of these people within community-based physiotherapeutic healthcare are inextricably linked.

This study was intentionally conducted with a small number of participants within NSW, Australia, to allow in-depth interviewing. It was decided to approach five physiotherapists in private practice (rather than salaried physiotherapists working in more institutional, community-based healthcare facilities, such as community health centres). These therapists visited clients in their homes, workplaces or recreational venues. This research decision was made with a view to accessing longer-term physiotherapeutic relationships in community-based healthcare.

Community-based physiotherapists within public and institutional healthcare tend to be less deeply placed within local communities than private physiotherapists. Community-based public physiotherapy practice also appears to be necessarily constrained by set policies related to intake procedures, amounts of therapeutic time allowed for client contact, and pressure of waiting lists. It was thought that privately practising physiotherapists might have more control over such factors and be able to monitor and respond to clients’ needs in a more individually customised way. The research was interested in the ways in which people in such situations might interpret their physiotherapeutic relationships, from all sides of that relationship. The research participants comprised:

- 5 community-based private physiotherapists in NSW
- 5 of their clients with severe chronic and complex healthcare issues living at home or in a group home
- 7 of their family members
- 6 of their carers.

The 2:3 ratio of male to female physiotherapy participants chosen for this project mirrored the overall ratio of male to female physiotherapists in general private practice, where 73% of physiotherapist were female (APA, 2005).
DATA COLLECTION AND ANALYSIS

Data Collection

Thirty-five semi-structured interviews were conducted (and recorded). Interviews held with physiotherapist participants were conducted individually and in the place where they felt most comfortable. All client and family interviews were conducted within their homes. This was considered necessary to ensure that the higher care needs of clients could be more readily and more easily satisfied during the interview processes. In some cases family members spoke on behalf of clients with speech impairments and one client used a communication augmentation device.

A focus group was conducted with the physiotherapists on their own. Meeting several times with participants helped to develop their trust when talking about the delicate issue of human relationships and how such relationships develop within home-based healthcare for complex, difficult health problems.

Data Analysis

Data analysis was an iterative process involving creation of phenomenological narratives with the participants and researcher immersion in and dialogue with the interview and focus group transcripts. From this process chunking of ideas were deeply reviewed to generate themes. Three themes were identified: being mindful, staying engaged and being responsive.

CONCLUSION

This chapter has presented the design and implementation of a study (Tasker, 2013) of the community-based physiotherapy relationships that develop between community-based physiotherapists, their clients, clients’ families and clients’ carers. The research produced rich and meaningful findings, which are illustrated in Chapter 4 and an insightful model for practice: Mindful Dialogues in Community-based Physiotherapy as presented in Chapter 5.

REFERENCES


CONSTRUCTING MINDFUL DIALOGUES


TASKER AND HIGGS


_Diane Tasker PhD_  
_Education, Practice and Employability Network, Australia_

_Joy Higgs AM PFHEA PhD_  
_Education, Practice and Employability Network, Australia_
3. NARRATIVE AS A LENS ON PRACTICE

Narrative is about transformation over time.
It’s about the relationships between
What we did yesterday and what we will do tomorrow.
It’s about what we do and how we describe.
It’s the way we talk about human beings.
Built into us is a narrative way of being.
We ascribe meaning and make sense of our lives through narrative.
It’s about how we make ourselves intelligible in the social world
Where we use stories to identify ourselves to others and to ourselves.
(Adapted from Kearney, 2009, p. 191)

INTRODUCTION

Interactions between people getting to know each other and working together can be seen as strongly narrative in nature. Narrative places emphasis on temporality (events occurring over time) and the telling of those events (Rimmon-Kenan, 2006). In this chapter, the concepts of story and narrative inform the author’s research into community-based physiotherapeutic relationships, arguing that stories are an essential part of human relationships. Mindful recognition of the part that narrative and stories can play within healthcare interactions can significantly contribute towards the efforts of practitioners to achieve person-centred and relationship-centred care for their clients.

NARRATIVE IS WHAT A NARRATIVE DOES

(Narrative is) someone telling someone else that something happened.
(Herrnstein Smith, 1981, p. 448)

Throughout history, stories have been used to communicate a unique account of events from the perspective of the storyteller, creating powerful word pictures for the listener to easily and clearly remember (Sorrell & Redmond, 2002). A balance of the narrative elements described in Table 3.1 might be recognised in what any of us would call “a good story”; that is, a thought to take forward, a message that resonates, creation of a memory, a thought or feeling provoked and an emotion to recognise. The meaning and significance of stories helps people to remember an issue over time, rather than just retaining the facts of the matter (Bruner, 1990). Stories can be from an individual or an interpersonal perspective and express interpretations of the way we view and make sense of the world and our experiences in it. In particular, stories interweave plot and character (Paley & Eva, 2005) to help people make meaning of the changing events that occur over time in their lives (Herman, 2007). A story recalls experience, and the
intention is often to relate it in a manner that stimulates a meaningful response and understanding from the listener” (Skott, 2001, p. 249). Such responses are inevitably subjective and integrated by what is termed narrative unity, that is, “the sense in which contingent and apparently disparate circumstances are brought together in a single thread, so as to focus the reader’s emotional response to the events described” (Paley & Eva, 2005, p. 97).

Table 3.1. Possible effects of story/narrative characteristics within stories and human interaction (derived from Aristotle, as described by Greenhalgh, 2006, p. 4)

<table>
<thead>
<tr>
<th>Story characteristics</th>
<th>Effect of a story’s characteristics within that story (Greenhalgh, 2006, p. 4)</th>
<th>Possible effect of a story’s characteristics within human interaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronology or temporality (The passing of time)</td>
<td>“The unfolding of events and actions over time” (p. 4)</td>
<td>A thought to take forward</td>
</tr>
<tr>
<td>Characters (The people)</td>
<td>People who “take action and/or respond to the actions of others” (p. 4)</td>
<td>A message that resonates</td>
</tr>
<tr>
<td>Context (The places)</td>
<td>“The local and wider world in which the characters enact their business” (p. 4)</td>
<td>Creation of a memory</td>
</tr>
<tr>
<td>Trouble (The action)</td>
<td>“A breach from the expected, as in surprise or “twist in the plot” (p. 4)</td>
<td>A thought or feeling provoked</td>
</tr>
<tr>
<td>Emplotment (The telling) *</td>
<td>“The rhetorical juxtaposition of events and actions to evoke meaning, motive and causality” (p. 4)</td>
<td>Recognition of an emotion</td>
</tr>
</tbody>
</table>

*See also Rimmon-Kenan (2006)

While all stories are narratives, not all narratives are stories. While the terms “stories” and “narratives” tend to be used interchangeably some authors use the terms precisely. For example, Paley and Eva (2005) referred to narrative as an account of the sequence of events and the causal connections between them, and gave examples of narratives that do not count as stories, including diaries, experimental reports and case histories. They argued that the difference between stories and narrative lies in the form and amount of organisation (narrativity) required to gain an emotional response from the listener. Stories involve a high level of narrativity and narratives a low level of narrativity. Regardless of terminology preference, human beings can be seen as narrators, with narrative a mode of transforming knowing into telling (Kearney, 2009, p. 49). Stories and narrative involve people’s efforts to manage space and time through their communication with each other. The integrating effect of the connection brought about by the use of narrative strategies within interpersonal interaction enhances the feeling of being together that human beings crave and need to create the feeling of being supported within healthcare.
Narrative to Form "Shapes of Time"

Wherever we look in this world, we seek to grasp what we see not just in space but in time as well. Narrative gives us this understanding; it gives us what could be called shapes of time. (Porter Abbott, 2008, p. 10)

Literary theorist and philosopher, Ricoeur (1983a), differentiated between two aspects of time; cosmic (chronological) and phenomenological (time as experienced by individuals) and posited that “chronological time becomes phenomenological or experienced to the extent that it is articulated through a narrative mode” (p. 52). Differentiation occurs between these two characteristics in practitioner–client healthcare interactions when practitioners seek clear information of events occurring over time without “literary, indeed emotional embellishment” of a narrative explanation (Hovey & Paul, 2007, p. 56). Practitioners need to exercise narrative vigilance to differentiate between “the emotional persuasiveness of the ‘story’ with the objective accuracy of the ‘narrative’” (Paley & Eva, 2005, p. 83). However, Hovey and Paul (2007) proposed that by honouring “the story” (how events are experienced), through the act of story sharing, re-interpretation of that story can occur as clients’ perspectives change over time.

Chronotope: Narratively Anchoring Dialogue in Time and Space

Within community-based physiotherapy, ongoing dialogue with people needing healthcare assistance better combines both the temporality of healthcare events that occur and the telling (experience) of those events contributed by people if that dialogue is to be narratively anchored in time and space. The concept of chronotope by Bakhtin, (1981) helps us understand the way that people can interpret the clinical relationships they develop in different contexts (time and space), in this case, within community-based physiotherapy. Bakhtin “envisaged all of life as an ongoing dialogue which takes place at every moment of daily existence. Life is by its nature dialogic. And so is discourse” (Noriega Sanchez, 1998, p. 52). Bakhtin borrowed the word chronotope from science to describe how time and space might be used in literature to provide a clear and understandable setting for events and for human experience of those events, thereby enhancing the meaning of that interaction. The word chronotope (literally meaning time-space) refers to “the intrinsic connectedness of temporal and spatial relationships that is artistically expressed in literature” (Bakhtin, 1981, p. 84). For this research project, the context of home and family provides just such a powerful chronotope, affecting all that follows with its overtones and prior understandings.

NARRATIVE TO INTERPRET HUMAN EXPERIENCE

Narrative can be viewed as a form of interpretation, telling human experience to better understand it. Ricoeur (1983a) drew on Aristotle’s work regarding poetics to explain how the use of emplotment allows people to make sense of their experience by organising it. Ricoeur developed his understanding of how people make meaning of their experience over time by integrating Aristotle’s work regarding emplotment with Augustine’s treatises on the nature of time (written between AD 397 and AD 398). Augustine argued
that “the measure of time is not to be found in things, but in the human mind” (according to Hausheer, 1937, p. 506).

**Mimesis: The Representation of Human Experience**

Ricoeur then proposed that narratives integrate the different aspects of time through a process he called mimesis (see Text Box 3.1). The term *mimesis* refers to the act of representation of human experience, where time is configured to compose an imaginatively ordered whole of events, agents and actions that makes activity intelligible” (Kearney, 2009, p. 58). Ricoeur (1983a) proposed three different mimetic (representative) stages or moments of time and argued that the moment of configuration (where interpretation occurs) was most important in expanding the world of the plot.

<table>
<thead>
<tr>
<th>Mimetic Moments in Time</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Prefiguration</strong> (mimesis 1) - Pre-existing knowledge and pre-understanding of the world (allowing action to take place).</td>
</tr>
<tr>
<td><strong>Configuration</strong> (mimesis 2) - The way in which narrative constructs a story through emplotment (interpretation occurs).</td>
</tr>
<tr>
<td><strong>Refiguration</strong> (mimesis 3) - The process by which we redefine ourselves through narrative (the story appears) (Derived from Ricoeur, 1983(a), Kearney, 2009, p. 58 and Alsaker &amp; Josephsson, 2009, pp. 59-60).</td>
</tr>
</tbody>
</table>

*Text Box 3.1.*

“Meaning has to be communicated before it can become meaningful, implying that the teller of and the listener to a story must reach a common understanding of the content of the story to communicate” (Alsaker & Josephsson, 2009, p. 66).

From within the field of occupational therapy, Alsaker and Josephsson (2009) explored the way in which women with chronic rheumatic conditions made meaning within their everyday activities. Drawing on Ricoeur’s (1983a, 1983b) work, their findings revealed that participants found meaning within the practical actions involved in everyday life. Alsaker and Josephsson speculated whether such meaning processes could be transferable to other situations and suggested that therapists could provide “try-out spaces” for different approaches to an issue requiring resolution (p. 66). With reference to community-based healthcare situations, where physiotherapy takes place within the day-to-day activities of people living at home, the particular context of the home setting and the ordinary life activities occurring there can be expected to carry a great many different and important meanings waiting to be communicated. Embodied human relationships with their complexities of thought and feeling could be included among those ordinary life activities.

**HUMAN RELATIONSHIPS: FINDING NARRATIVES OF EMBODIED EXPERIENCE**

The use of the lens of embodiment within physiotherapy allows an “orientation towards the whole person” and encompasses the human body and its healthcare issues (taking an objective view), people’s experiences (taking a subjective view), and social determinants...
of health such as legislation and institutions (taking a societ
al view) (Nicholls & Gibson, 2010). Embodiment, therefore, involves “respec
ting diversity, eclecticism, deviation, and difference, and having an inclusive attitude to the ways people view their own embod
iment” (p. 503). Gibson (2010) expressed the concern that physiotherapy’s
technical bias towards predominantly physical and functional goals in therapy could actually result in clients’ marginalisation within society. Physiotherapy has historically
adopted a “body-as-machine” approach to people’s healthcare issues, possibly in relation
to its massage history and in an effort to better define and assume a particular area of
health work (Nicholls & Gibson, 2010; Nicholls & Holmes, 2012). Nicholls and Holmes
(2012) further argued that physiotherapy as a profession might have closed down
possibilities to respond effectively to the more recent expectations of person-centred
healthcare through its adoption of the body-as-machine metaphor, along with other
disciplinary strategies designed to manage the sensitive issue of touch within
physiotherapy. Natural science sought to reduce the complexity of thought and feeling
with empirically proven explanations, building on the scientific investigations of brain
structures and human behaviour (Varela, Thompson, & Rosch, 1997). In contrast, social
science sought to explore the realms of human experience and expand understanding by
using reflection, interaction and interpretation.

Academic and philosophical tension occurred at the interface of these different areas of
enquiry. Varela et al. (1997) described this interface as being at a crossroads, “janus-
faced”, “looking down both roads at once”, but also with an inevitable circularity. Such
circularity also occurs as we move back and forth between the inner and outer terrains of
our existence, the body as our physical, biological existence but also as our contextual,
experiential and phenomenological existence. An example of such circular and embodied
connection is seen in a study of Norwegian psychomotor physiotherapy, in which a
narrative approach which involved client–therapist reflection was used to assist people
with chronic pain (Øien, Iversen, & Stensland, 2007). In this study of clients’ narratives of
embodied experience, findings showed a connection between clients’ pain symptoms and
their sensations of self–body detachment, connected to stories of difficult interpersonal
relationships. Assuming a “not knowing” position, therapists adopted a curious attitude,
searching to get to know individual clients’ narratives to then help them to work through
their present difficulties and develop a more constructive narrative to manage their pain
more effectively. Client, Gina described the therapy process as a change from
experiencing herself as an anxious mind to experience body and mind as more of a unity.
She was moving back into her body; a change formulated as a narrative of awakening.
The themes described in this study tell a tale of disconnection and reconnection. Below, I
list these themes as they occurred in the article written by Øien et al. (2007). They
poetically tell an interesting and powerful story from the client’s point of view.

Being divided in body and mind
   My back as a tortoiseshell
   I’m not to be blamed
   Breathing more deeply
   My legs: My “stepchildren”
   My body was asleep.
(Derived from Øien et al., 2007, pp. 34-36)
Using an embodied view, people are not only their bodies but also have their bodies (Merleau-Ponty, 1962). Storytelling can become a personal mental tool, making meaning of the strange landscape of illness, injury rehabilitation or disability. Narrative assists to impose a coherent structure onto people’s experience, creating movement from a negative to a positive viewpoint for them (Baumeister & Vohs, 2002). Physiotherapy practice might be improved through the use of narrative by sensitising practitioners to that complex process involving the lived experience of their clients. Soundy, Smith, Cressy, and Webb (2010) discovered that physiotherapy students found immersion in the emotional lives of other people difficult to manage. Frank’s (1995) narrative styles (see Table 3.2) were introduced to help them understand the lived experiences of people with spinal cord injury.

Table 3.2. Frank’s “Wounded Storyteller” narratives (derived from Frank, 1995)

<table>
<thead>
<tr>
<th>Narrative style</th>
<th>Restitution</th>
<th>Chaos</th>
<th>Quest</th>
</tr>
</thead>
<tbody>
<tr>
<td>Plot</td>
<td>“Yesterday, I was healthy, today I am sick, but tomorrow I will be healthy again” (p. 77)</td>
<td>“Living a life of overwhelming trouble and suffering”; “life is never going to get better” (p. 113)</td>
<td>“Something can be gained from this experience” (p. 115)</td>
</tr>
<tr>
<td>Type of story/narrative</td>
<td>A type of naming story where the teller seeks the true name of the disease and maybe his/her own true name as well</td>
<td>An anti-narrative; chaos experience “cannot literally be told, it can only be lived” (p. 98)</td>
<td>A self/other story of the teller’s journey, bearing witness to the teller’s transformation of self and character</td>
</tr>
<tr>
<td>How the story works</td>
<td>Promises hope of “outdistancing or outwitting suffering” (p. 97)</td>
<td>Describes the despair and loss of hope where life appears meaningless</td>
<td>Searches for a different way of being ill. Accepts disability. Embraces uncertainty and seeks to use the experience</td>
</tr>
<tr>
<td>Active player</td>
<td>The remedy and/or the health professional</td>
<td>The voice of the client is lost in the chaos</td>
<td>The client now has a voice and a story to tell</td>
</tr>
<tr>
<td>Power</td>
<td>Sustains the illusion of permanence. Conforms to hegemonic views regarding cures in healthcare</td>
<td>Shows how quickly the foundations of any story can fall away. Allows the client to be heard; including and tolerating the client as a relevant member of society</td>
<td>Gives the client a voice. Holds chaos at bay for the client</td>
</tr>
</tbody>
</table>

*See also Rimmon-Kenan (2006)
Although all the student participants found “quest” stories admirable and “chaos” stories depressing and difficult to hear, the first year physiotherapy students generally seemed to show more empathic responses than the third year students, who “seemed to unify a voice of physiotherapy and were perhaps more receptive to an ideal patient or narrative” (p. 56). Soundy et al. (2010) suggested that this could indicate a loss of empathy through training. They further proposed that “for the patient, being heard by a therapist, regardless of the story, has value” (p. 56) and suggested that education and training regarding the use of such narrative styles could help physiotherapists in developing their treatment approaches.

Within narrative approaches to healthcare practice, there are different narratives to be told (Greenhalgh, 1999). Health professionals narratively interpret and integrate many different “secondary texts” (or stories). For example, there is the experiential text (the meaning given by the client to the experiences), the physical text (the information recorded from the examination of the client), and the instrumental text (the information from special tests such as radiographs) (Loftus & Greenhalgh, 2010, p. 3). This research pays particular attention to the experiential texts of clients, families and carers.

CONCLUSION

The use of a narrative approach to studying healthcare interactions provides insights that enable practitioners to understand more deeply their practice with and for clients or patients (Charon, 2006). The research discussed in this book section extends existing research by exploring the multiple perspectives of therapist, client, families and carers (with a variety of client ages and conditions included) within the context of community-based family care and with a narrative ear.

Human beings are narrative creatures and are essentially self-interpreting. (Titchen & Hobson, 2005, p. 13)

REFERENCES


TASKER


Diane Tasker PhD
Education, Practice and Employability Network, Australia
4. HEARING THEIR VOICES

Voice is the right and the ability to make oneself heard and to have one’s experiences and perspectives available to others; to participate in the construction of the self and to decide how to represent that self to others. (Ashby, 2011, para. 3)

Human dialogue involves a meeting of voices. When one voice is quieter, more care and attention is needed if the humanity and needs of the person behind that quieter (or even lost) voice is not to be overlooked or ignored. As healthcare professionals, we must therefore try to access those quieter voices, especially when we are attempting to improve our professional practice with and for them. To accomplish that aim, we need to hear their voices. In this chapter, the words of client participants in my qualitative research project, Mindful Dialogues in Community-based Physiotherapy are presented simply and as they were spoken. The complexity of such communication can be more fully appreciated in situations where clients also have difficulties in expressing themselves due to physical or cognitive impairment. In such cases, the contributions and sensitivity of family and carers play an important role in the ability of a client to be able to participate in conversation at all. The poetic simplicity of all the participants’ voices in this chapter speaks easily to us as readers, opening up opportunity for deeper understanding of their situation and the relationships they have with their physiotherapist. Learning about these clinical relationships may help practitioners better understand and develop their skills in their relational practice. Recognition of the poetics within people’s communication may also give healthcare practitioners an added perception to better appreciate clients’ meaning in healthcare conversations.

LISTENING TO CLIENT VOICES

Within the qualitative study of community-based physiotherapy described in Chapter 2, client participants and their families spoke of their relationship with their visiting physiotherapists. The participants in this research provided insights into the development of community-based physiotherapeutic relationships from varied perspectives. In the same way that a practising physiotherapist will listen to many different voices in a community healthcare situation, as a researcher, I also sought to listen to the many voices of this study’s participants, including the quieter voices of clients with communication difficulties. The data generated from research interviews lay quietly on the page, waiting to be read and understood.
Some of the participants were able to speak easily but some had impedances of speech and in one case, no speech or augmented speech only with a device producing typed words. Qualitative researchers pour over such data, searching for meaning in phrases and words, which seem to stand out from the generality of the data. In many cases, poetic resonance of particular phrases can assist the researcher to choose themes or messages from the data.

In the following pieces, client participants and then a family tell us about the relationship they have with their visiting physiotherapist and what that means to them. The words were drawn directly from the data, keeping true to the chronological order of their speech with minimal extraction of any words. In some cases extra words of explanation for context were added but put within brackets to set them aside from the participants’ words. Interestingly, when the clients’ words were arranged on the page, real poetic flow emerged. When people feel strongly about something, they express themselves as clearly and strongly as they can in their conversation. Through the words we choose, we try to send messages to other people, telling them about our feelings, our wants and desires, what is happening for us, what we want to happen – our story. These are stories told to me by Eric, Joanne, Dennis, Jenny, Jack and Jack’s family (real names have not been used).

**Eric**

Eric was well-educated and in his nineties. He had worked as a specialist doctor. Despite his health difficulties of progressing dementia, back pain and mobility problems, Eric’s wife and daughter assisted him to carry out activities in his daily living the way he wanted, gently filling in any conversation gaps that occurred. Social conversation and reminiscences assisted Eric to stay focused, along with a cup of tea. While there was some fluctuation in his ability to remember events and names of things, Eric had a very clear and pragmatic view of the way he and his physiotherapist, Barbara, worked together. From Eric’s words, we can see that the relationship he had with his physiotherapist, Barbara, was intertwined with the activity of their physiotherapy sessions, in particular, walking. The social and physical components of Eric’s physiotherapy session appeared to be equally important to the overall physiotherapy process for him, (possibly in part due to his need for regular re-orienting and supplementation for short-term memory deficits). Her particular way of interacting with Eric lends support for the conclusion that there is a need for subtlety and complexity in such physiotherapeutic relationships. I argue that the nuances of these interactions/relationships are far more important than we (health carers and healthcare literature) have acknowledged up to now.

**The walking’s the main thing really**

*The physio makes me walk up and down the passage every time.*

*I don’t mind.*

---

34
I’ve kept going.  
It won’t get better.  
I don’t really know what I wanted her to help me with,  
but I want to be able to get around readily and comfortably.  
The walking is the main thing, really.  
When I’m doing the walking, she stands behind me.  
She doesn’t actually do other things  
but she makes suggestions as to what I can do.  
It’s just comfortable working.  
We talk about things that are going to happen or have happened.  
We talked about her trip to New York.  
I went there.  
I didn’t have this difficulty then.  
I just can’t think of the name of the place.  
I’ve had some difficult times, times when it’s difficult to get going.  
She’s very encouraging.  
That works but there are some things that are just there.  
If I’ve had a bad night, she just takes me as I am and we do what I can.  
So we’ll go to the far end; then we’ll swap and she’ll tell me how good I am.  
[Eric laughed].  
If I’m not tired, I’ll walk fairly straight and lift my legs.  
But when I get tired, I go floppy.  
She lets me go while I’m safe but we swap round at the end of the passage.  
Then I have a spell and she talks to me.  
I mean we’ve worked.  
She enables me to do things that would not have been possible otherwise.  
She makes me walk around everywhere [Eric laughed].  
She hasn’t pushed or anything,  
She comes here once a week, yes.  
She just works on my doing things  
She just fits in.

The picture forms gently in one’s mind of an elderly man and a community-based physiotherapist quietly making their way down the corridors of his home, he with a walking frame and she standing just behind and beside him. The man is trying to keep on walking and she is beside him, making it more possible. His words encapsulate their relationship and open up confirmation of the value of walking beside someone as they try to manage chronic healthcare issues.

Joanne

At the time of the study Joanne was a lady in her forties who experienced a severe acquired brain injury. She lived with her husband with the assistance of paid carers during the day. Joanne was able to mobilise around her large and airy house in her power wheelchair. She really still wanted to walk, although she needed assistance
to do so and found it quite scary, due to her difficulty with balancing. The expectations of her family may well have been contributing to this situation although that was not said to me directly. Her speech was limited by dysarthria (a difficulty with the muscles of speech which causes speech to be slurred) but we were able to manage our interview together by my checking that I had understood what she was trying to say at regular intervals during the interview.

**I know now where I stand**

I didn’t know what was going to happen.
I thought I would be normal.
I thought it would happen quickly.
I was in rehab for one year and then I came home.
I was uncertain with her [the physio]
but she’s a very comfortable person to talk with and friendly.
She does everything, talk, touch, help.
I wouldn’t let everyone touch me.
She’s a comfortable person and friendly.
When I needed (to do something better), she would tell me.
If I did something wrong, she would tell me.
Once she said to me - if I cried, she would sit there and talk to me.
She had feeling.
It’s the person.
It’s the person.
It’s hard to put words to it
[Joanne put her hand over her heart]
She’s like my family, very calm.
It’s the person.

I have gym, twice a week [with a personal trainer].
He helps me walk but it’s not the same.
I have two carers, but it’s not the same as my relationship with Lynne.
She shows concern for me as a person.
She’s sensitive to my feelings.
A lot has happened.
I remember, when she told me I may never walk.
She came to help me.
I was upset, but she was honest and that was okay.
She said now it depends on me.
I was prepared to push,
I was determined to walk
But I’m frightened of falling.
Since then, she didn’t want me to break something.
Yes, I know now where I stand.
I feel more determined.
She knew instinctively (how to make that call).
Joanne’s words reveal her difficult process of rehabilitation after an acquired brain injury, as she tried to find her place in the midst of the chaos that follows such injury. Her last comment in the vignette above; “The accident changed how I feel (about) people, life, everything”, reveals a true chaos narrative (Frank, 1995). Joanne’s initial narrative also described how she tried to assume a restitution narrative (Frank, 1995) at first; as any of us might also do, believing that she would get better.

Smith & Sparkes’ (2002, 2004) study of narrative hope for people with spinal cord injury also used Frank’s narrative styles as a lens, arguing that a client’s hope of resuming walking activity could be seen as a “concrete hope” but the holding out for such a specific resumption of normal activity in the face of permanent impairment might actually impede that person’s ability to “re-story” their body-self relationship. Although Smith and Sparke’s (2002, 2004) study concerned spinal cord injury, Joanne’s efforts to resume functional walking may have made her narrative journey more difficult, perhaps tipping her back into a chaos narrative (Frank, 1995). These difficult issues needed to be worked through with the assistance of her physiotherapist. Her relationship with her physiotherapist, Lynne, sustained her through the process into which she had been thrown (Heidegger 1962). Joanne trusted Lynne and when the situation arose where it became clear that her walking was not going to become independent (as everyone had hoped), Joanne was able to gain some acceptance of this situation, knowing that both she and her therapist had tried their best. She said, “Now it depends on me”.

This last comment gives the idea that Joanne may have started to “take the reins” back from her therapist as part of that acceptance, possibly starting to make her own personal decisions about what she felt she could realistically do herself. Such balancing of the gradual resumption of a person’s decision making for themselves with the emotional difficulties related to disappointment in limited physical progress is part of the rehabilitation process. Joanne had found her physiotherapist, Lynne, to be understanding of her fear of falling and supportive of her generally. She also appreciated the emotional support she gained from her. Such support and understanding proved to be an important part of her ability to come to terms with what she was able to achieve with her mobility.

The presence and assistance of an experienced physiotherapist can be most helpful for clients and families but for the therapist, there are also difficult professional decisions to be made along the way, regarding assistance, dependence, honesty and the maintenance of hope. In all of the conversations with clients and families in this study, I noted that hope existed as a comfort and a sustaining force in the difficult healthcare situations inhabited by the participants. Within recent literature (Soundy, Smith, Butler et al., 2010; Soundy et al., 2011) discussion has...
been opening up regarding the importance of hope in physiotherapy-assisted rehabilitation processes. The initial hope of people after injury relates to restitution narratives (Frank, 1995), where there is an expectation and drive towards the resumption of normality returning the body to its former health and function, particularly the activity of walking. Gibson and Teachman’s 2012 study further suggested that physiotherapists’ participation in decisions with clients and their families “to walk” or “not to walk” can be quite frustrating for physiotherapists. In Joanne’s situation, the decision whether to walk functionally (but with risk) or not had obviously been a very difficult one to make and it was not clear if Joanne had really decided how she would be proceeding.

Dennis

At the time of the study Dennis was a young adult who had had a devastating car accident, causing a high level, incomplete spinal cord injury and some acquired brain injury. He lived in an upper storey inner city apartment with a large balcony and received 24-hour carer support. His physiotherapist, Adam, visited him for movement and walking activities two or three times each week. On most days, an older lady neighbour visited him for coffee and a chat. When I visited him, Dennis was sitting in a large, padded, care chair in front of the TV. I understood from his physiotherapist that Dennis had decided not to use a power wheelchair but preferred to be pushed around by his carer. His carer was in the adjacent bar style kitchen, carrying out housework activities as we conducted the interview. Dennis was happy to be included in our research project. He obviously valued his contact with his physiotherapist and what that intervention had assisted him to do.

That’s as far as I can go

I had a car accident
where I smashed into a concrete telegraph pole
and I ended up with a C2 incomplete tetraplegia.
I also had a closed head injury
as well as small memory problems.
I went to rehabilitation (rehab),
I went to brain injury rehab and spinal injury rehab.
I started seeing someone else for a while as a physio
and then somehow it worked out that he [Adam] came
and he has been my physio ever since.
Yes, everything has worked out really well.
We’re at that stage, we’re like mates,
we always laugh and muck around together and stuff
but also he’s a really good physio.
My vision originally, was to get back walking,
to get back to normal hopefully.
After a certain amount of time,
I realised that wasn’t going to happen by itself.
So basically, now we keep stretching all of my limbs
and everything, ranging my muscles.
I do a walk with him every time he’s here.
He comes three times a week
and what I basically want from him now;
I’ve said “I want to keep walking a bit each time
and get to the stage where I can just keep all my muscles
and everything working to a certain point
so that when and if they do find a cure...
Well I’ll say “when” because I’m optimistic.
When they do find a cure, I’ll be ready to do it;
ready to go forward and I won’t have lost anything.

I wouldn’t say he’s tough. [talking about Adam, his physio]
He always encourages me to do things
but he knows that if I don’t want to do something, that’s my call
and he won’t push it any further
because he knows how far... [I can go].
He knows that I push myself really far
and he knows that if I’ve said “that’s as much as I can do”
that’s pretty much as much as I can do.
When we’re walking,
if I’ve said “Oh, that’s as far as I can go”
he used to say “Can you do a few more steps?”
and after a little while I would just look at him
and he would stop because I really push it as far as I can
until I say “I’m buggered”.
I get fatigued a lot.

Maree [my carer] and I are the
“A” team but Adam also attends to me himself.
He does caring things, carer type things as well,
Yep, more than just a physio
That’s what I think.
The good thing about Adam is that
I can always get up and walk with him.

Dennis’s story also holds hope as a central tenet but it had been “put on hold” to a
large extent. Dennis had realised that he had “gone as far as he could go” both in a
general sense and every time he tried to walk. While he appeared to have
abandoned a full restitution narrative in his life story, the hope of a cure still
seemed to linger. He felt that he needed to stay ready for any new scientific break
through which might once again offer him a chance of recovery. Whether Dennis
really believed this to be a realistic possibility was not clear, but it was clear that
hope was still a comfort and a reason for carrying on with life.
The way that Dennis spoke of his hope for a cure was quite casual, almost automatic. His view is supported by the work of Smith and Sparkes (2005) who argued that “hope for a ‘cure’ when framed in terms of restitution is often articulated in a taken-for-granted manner that lacks reflexivity” (p. 1102). As Smith and Sparkes (2005) also commented, it is a matter for conjecture as to why Dennis spoke of this hope in the way he did; was it a genuine feeling or rather the way that he thought people would expect him to feel? Dennis’ physiotherapy was an important activity for him. He appreciated Adam’s continuing visits and the comradely interaction they had together and trusted Adam’s professional knowledge. Adam’s friendliness seemed to contribute to Dennis’ self-esteem.

With his particularly high level of disability, Dennis also depended on Adam for assisted walking. Although the walking activity was not for the usual functional reason of getting from one place to another, it was important for him as an exercise opportunity and provided some context for his relationship with Adam. A question also arises as to how much people maintain activity for its own sake (and its functional benefit) and how much it’s about continuing their relationship with their physiotherapist because they enjoy the interaction and support. From yet another viewpoint, Smith and Sparkes (2005) noted that men with spinal cord injury may “quickly learn that they need to express certain kinds of hope if they are to maintain relationships with others and secure the professional services they require” (p. 1105).

The place of continued activity and interaction plays an important part in the maintenance of hope. It is hard to imagine a situation for oneself where the only chance you have to do what was an ordinary activity like walking is when a professional physiotherapist visits to assist you. The absence of opportunity to do ordinary activities (like walking) could have signalled a loss of hope for Dennis. The ability to at least maintain some semblance of walking might well give a feeling of normality and a means of being able to view a road ahead of some sort.

Jenny

At the time of the study Jenny was a young woman, who lived in a group home. She had profound physical and intellectual disability and was unable to walk, talk or care for herself in any way. Her family was very involved with her care and the group home encouraged their involvement in every way possible. Jenny had little voluntary movement. She attended the research interview with her parents and lay in a side-lying positioning aid for comfort. When she made any sound or movement, her parents and I would direct the conversation towards her, in an effort to include her within our discussion as much as possible. Jenny’s presence was essential to the interview, affecting every word spoken by everyone present because it was “all about Jenny”. She was “there” and “with us”.

*What our daughter Jenny likes and how life is for her*

*Jenny doesn’t want us to sit beside her.*

*She’s a sticky beak all right.*
She’s eavesdropping on our conversation.
Jenny doesn’t want us to just sit beside her,
we have to sit on the lounge with her and cuddle her.
At home, she was always in someone’s arms.
Even if people came to visit, she was always nursed
and that was part of how we communicated with her.

We used to lie her on the bed
in the morning or at night.
You’d lie in,
it would be still
and you’d just be lying there and talking to her.

If you go to the theatre or even movies,
you hold her hand.
There has to be some kind of interaction.
If she starts getting grumbly,
in the past I would have just thought
“Oh, Jenny might be getting a bit tired”
but now you’re more aware.
Maybe she needs to do some side lying
or she needs to change position.

It was important to highlight Jenny’s need to be communicated with. On the next page, I have included comments from Jenny’s mother about her daughter. I follow this with poems written for Jenny; firstly, an example of “derived” poetry (A conversation with Jenny) and then an example of “interpretive” poetry (Listen to me). I wrote the interpretive poem based on my clinical experiences with other young adults like Jenny (and in keeping with what I had learned about Jenny, particularly), in an effort to increase the sense of her presence within the research and the difficulty she and her carers faced in joint social situations. I felt that Jenny needed to have her introduction like the other participants. The following piece of derived poetry, taken directly from the data, gives an essential and distilled feeling for the interaction between Jenny and her therapist, John. Its message is reinforced by its juxtaposition with the interpretive poem, Be quiet, that follows.

A conversation with Jenny
What’s going to happen?
Where are we going?
Keep an eye on her face
Her face will tell me.
She will look
She’ll turn her head when her carer and I talk
But I don’t talk to staff about her.
I have a conversation with Jenny.
Jenny’s interaction with her physiotherapist was very physical and sensory in nature (relating to the hands-on nature of her therapy). With the absence of verbal interaction, these modes of interaction appeared to have become enhanced. Jenny’s mother had become very aware that non-verbal communication was very important to Jenny. Verbal communication by her physiotherapist, John focused on communicating with other people about Jenny and this included his speech to her. His interaction with her carers was all about advocating for Jenny.

Be quiet (An interpretive poem for Jenny)
Listen to me.
I need you to listen.
I can’t communicate as well as you.
So I need you to listen and hear me!
(Tasker, Loftus, & Higgs, 2014).

Jack
At the time of the study Jack was a young man (in his late twenties) who had had a severe acquired brain injury from an accident as a young teenager. After being in hospital for over a year, he came home to live with his family. Visiting carers provided extra help. When I visited Jack’s home to conduct our research interviews, we all sat around the kitchen table. Sue, Jack’s mother, felt that he would feel more comfortable with his family and carer present. Jack sat in his wheelchair at the table with his augmentative communication device on the table in front of him. (In the story below the CAPITALS are Jack’s words communicated through his augmentative communication device rather than being normally spoken.) His carer, Honor, sat beside him to help him as needed.

“I WAS TOO YOUNG”
HELLO, HOW ARE YOU?
I WAS TOO YOUNG - IT SUCKS
[The physio] PRODS [But] THAT IS FINE
YES, THAT IS FINE MOST OF THE TIME
[I feel] GOOD [when I work with Karen] I LIKE HER.
WORKING WITH MY PHYSIO IS HARD WORK AND FUN.
[What do you know about your physiotherapist?] I AM ONLY CONCERNED ABOUT MY ABILITY.
[I can] WALK IN THE WALKING FRAME
THE ACTUAL [Physio] WORK CAN GET BORING.
[What do you want your physio to be like?] LADY OR MAN? LADY OR MAN?
BE HILARIOUS AND FUNNY
For Jack, his physiotherapy was a productive activity, contributing to a sense of purpose and helping him to continue with assisted walking at home. The fun came from the humour in the physiotherapy sessions as Jack loved to joke with his carers. It was of note that the therapist appeared to be aware of Jack’s need for fun and had the sensitivity to incorporate it into his therapy. It became very obvious to me as I looked at the transcripts of our interviews, that despite my best efforts to include Jack in the conversation, the effort and difficulty for him in typing out words on his communication device made his participation in our conversation a trial for him. Jack’s carer and mother seemed to monitor Jack’s feelings and possible levels of stress quite carefully, often inserting humorous comments to keep the conversation going; trying to engage Jack with a view to encouraging his participation but also managing any possible frustration that might occur in the more formal situation of our research conversation.

Unless he had a very definite comment to make or I addressed him with a direct question, Jack mostly participated in the activity of communication in a peripheral and physical way. In our first interview, he contributed facial expressions, laughter and gestures and was obviously interested but in our second interview, Jack’s father joined us and the dynamics of the group changed. Jack seemed to become tired and bored. It is possible that he viewed his father as competition for attention. He asked to leave and, as I had given him a gift of chocolates, he went off with his carer to his bedroom. Sometimes, Jack repeated his comments. At first, when reviewing the transcripts, I wondered whether this may have been due to neurological perseveration (an involuntary repetition of verbal comments) but on further consideration, I interpreted the particular comments that he had repeated, as issues he wanted to emphasise. Occasionally Jack made comments about something he had been thinking about but by then the general conversation had moved on. Some of this difficulty was clearly due to the amount of time that it took him to type words, which may have also contributed to his repeating phrases, perhaps a way of drawing our attention back to his contributions when we had moved on too fast in the conversation for his communication strategies.

“Whose Voice is it Anyway?”

In the process of trying to draw out the “voice” of the client participants, I became aware that where the ability of clients to communicate and speak was decreased, families, carers and therapists would increasingly try to speak and advocate for that client. I began to ask; “Whose voice is it anyway?” (Ashby, 2011). Managing
communication with people who have difficulties with cognition, comprehension and expression presents a very difficult and delicate area in healthcare.

My emerging themes were drawn directly from the data utilising the words used by participants. This allowed the authentic voices of the participants to emerge and reveal their personal experience. As Vanderstoep and Johnston (2009, p. 194) said, “The personal voice is the most authentic, and any movement away from personal experience is a move away from authenticity”. Recognising that authenticity allows us not just to listen to the voices of participants but to hear them better (Spivak, 1988). The narrative contributions of participants also assists us to remember what they are trying to tell us rather than just the bare facts (Bruner, 1990).

LISTENING TO CLIENTS WITH THEIR FAMILIES AND CARERS

Community-based physiotherapists come to visit clients to assist with their healthcare issues but inevitably end up communicating with families and carers as well. The voices of the clients in this research are delicate and quiet in nature. The meaning that clients, families and carers gained from their interactions with their physiotherapists was distilled by bringing all of their words together in a way that they may not be able to do in normal conversation, given the difficulties they experienced with speech, cognition and the difficulties they may experience managing a conversation with someone. Thornquist’s (1997) study noted that even when clients are able to communicate independently, physiotherapists may often need to negotiate families’ interpersonal communication styles in order to enhance a client’s “voice” within home-based physiotherapy. Findings from this research support Thornquist’s observations but I would also argue that it should be a matter of concern for physiotherapists to listen and attend to the voices of carers as well as clients in their overall care for community-based clients and families. In the following section, I have constructed another text from one of the family interviews where the family told me a particular story to describe how Jack interacted with his physiotherapist, Karen. The conversation was an integration of contributions from everyone present. Jack’s contribution was mainly physical but his place in the following family conversation seemed very relaxed.

Jack and his family:
There’s a right way and a wrong way and there’s “Jack’s way”

He was such a flexible kid. His physio was amazed at how he could do something. We came up with the saying: There’s a right way and a wrong way and Jack’s way.

One day, his physio said to Jack, “Come on, we need to lift your head. Alright, now how did you raise your head the first time, the eyebrows?.” (Jack raised both his eyebrows as high as he could.) (Everyone laughed). The (rehab) physio said “It’s the first time in all my years of practice that I’ve seen someone use their
eyebrows to actually stand up." So as I said, "There's a right way and a wrong way but Jack found the 'Jack way'".

Interviewer: And what does his physio, Karen, think about Jack's way?
She'll say, "Not that way, Jack, my way".
I think that she has probably compensated for Jack's way.
She's kind of twigged it a bit [the physiotherapy process] so that he feels that he's still doing it his way, but she's actually got her way too.
(Jack was nodding).

Sue: (Jack’s Mum) It's a bit like a husband and wife thing, you know.

Honor: Yes, she (the physio) picks up things. A couple of months back, Jack was doing this particular exercise (sit to stand practice) in his bedroom and he'd been doing it for about a month between visits and we thought "oh he's doing so well with this, look how straight he's standing".

Karen: (Karen, the physio came, stood back and watched him and then she smiled and pointed.)
You do realise ... because I had a mattress under Jack's bed and he was pushing back against it (with his lower legs) to stand up (rather than pushing up through his feet). It was subtle enough that we didn't pick it up. But he knew he was doing it.

Sue: We were standing beside him so we couldn't see, that he was doing that.

Jack: (Jack was laughing and putting his thumb up.)
INCREDIBLY FUNNY, ACTUALLY HILARIOUS.

In this conversation, Jack, his mother (Sue) and his carer (Honor) told me a story to demonstrate that while Jack had his own way of approaching things, his physiotherapist, Karen did too. In this therapy story, Jack's physiotherapist, Karen, was able to help correct Jack's standing exercise in a way that fitted in with Jack's way of doing things. He enjoyed a good joke and Karen understood that. Jack enjoyed this story-telling exercise and contributed to this story in a very physical way. He took part in our conversation with gestures and facial expressions; and gave a very funny demonstration of the way he used his eyebrows to help get himself moving from sitting to standing. His participation did not need much typing (on his communication device) and our conversation seemed to be more enjoyable for him because of that. In some ways, this style of conversation could be viewed as more meaningful than usual for Jack, due to the effort taken by Honor and Sue to make the interaction relevant to him. They made space within the conversation to direct comments towards him in such a way that he was able to join
in with the activity of conversation, without having to type his responses. Despite his lack of spoken words, Jack also had the last written word, much to his satisfaction.

Jack’s contributions seemed to be enhanced in this particular joint conversation. The very personal knowledge that family members had of each other may also have assisted Jack to communicate and interact with his physiotherapist. Such informed interaction is of great help in the planning and carrying out of therapy care. The participants had taken great care to develop meaningful relationships and communication. There was an innate awareness of the importance of good relationships by all concerned. The dialogic interaction that took place between participants here was a good example of how experienced and caring family members and carers can help clients to take part in the activity of a conversation by “patching the narrative” with and for them. Physiotherapists also use a “patching the narrative” approach (see below) to increase social focus on the clients’ situations and concerns.

PATCHING THE NARRATIVE

“People with limited communication skills are likely to be dependent on the involvement of others to act as advocates, facilitators or interpreters, which inevitably begs the question of ownership of the message” (Grove & Bunning, 1999, p. 191). Although this seems to be stating the obvious, this study does highlight the difficulties carers and therapists face when working with people with communication impairments. This will always present difficult challenges for community-based physiotherapists as they seek to balance communication with and for clients with significant disability and communication difficulties. In trying to form a holistic view of a client’s situation and planning how to proceed with physiotherapy processes, I propose that community-based physiotherapists actually rely on “patched narratives”, which combine the knowledge that carers and family have about the client, along with direct communication with the client and the therapist’s observations of the client in their particular setting.

This term, “patched narratives”, acknowledges that the story that the therapist builds from and about their client cannot always be fully owned by that client. Perhaps it is not possible for anyone to fully own their own narrative given the essentially dialogic nature of human affairs and thought. The particular human condition of clients with chronic and complex health problems may also dictate a degree of quietness in clients’ voices and further limitations both in the stories they live out and the stories they want to live out. However, visiting therapists still need to try and hear their voices as much as possible, in order to act and advocate for them. Such patched narratives can only be constructed through on-going communication between clients, families and carers through multi-voiced and continuing conversation.
BUILDING DIALOGUE THROUGH MULTI-VOICED CONVERSATIONS

How do community-based physiotherapists manage their communication with clients who have varying levels of communication ability and the many different carers and family members around them? When talking with Eric and his family, it was noticeable that his wife and daughter contributed to the conversation in ways that enhanced Eric’s voice, especially when he experienced memory problems. For Jenny who was unable to communicate verbally or with assistance, she was spoken for in any conversation about or with her although her carers and family tried hard to include her and refer to her whenever they could.

This could be seen as people talking over the voice of clients, for example, in Thornquist’s (1997) study, where a wife over-spoke her husband and the physiotherapist needed to use her body, available space and choice of communication styles to try and balance the communications of husband and wife. In the participants’ situations although such over-speaking might sometimes occur it seemed to happen less where carers were mindful of their clients’ communication difficulties. In the above examples, clients depended on the conversational initiatives of people who knew them well to allow the creation of their stories.

In a conversation with Jack and his family, Jack’s voice and experiences were actually partially spoken by other people (in this case, his mother and his carer). His communication difficulties greatly limited his verbal participation. He found it more enjoyable to join in the activity of conversation by acting and allowing people who knew him well to speak for him. The humour and flow of that conversation could then proceed and Jack was a part of it all. Indeed he was also the reason for it occurring and he showed how pleased he was by nodding, laughing and giving a thumbs-up sign. He also had the last words, “INCREDIBLY FUNNY, ACTUALLY HILARIOUS”.

The word in language is half someone else’s. It exists in other people’s mouth, in other people’s contexts, serving other people’s intentions: it is from there that one must take the word and make it one’s own. (Bakhtin, 1986, pp. 293-294)

Literary critic and philosopher, Bakhtin said what we all know intuitively at some level; we depend on other people to build useful language through the development of conversation between us. This is dialogue. People are familiar with the concept of a monologue, where only one person speaks (even if other people are present) and dialogue which occurs between two people in a reciprocal interaction (sometimes we may also speak of having a dialogue with oneself). These ideas can also be applied to clinical interactions between a physiotherapist and a client, especially in one-to-one interactions. However, in home-based healthcare, the communication arena can present differently. Clients may need significant assistance from their carers and family with planning activities and carrying out movement. In many home-based healthcare situations, there can be many family
members and carers, who help to care for that client and they will also communicate with the visiting physiotherapist. For physiotherapists, lines of communication become multi-voiced.

**Polyphony**

Community-based healthcare practitioners may often feel as though they have strayed into the pages of a novel as they enter very complex healthcare situations in the community. Clients with communication difficulties need the presence and contributions of other people to be able to create and communicate their story. In literature, authors seek to populate stories with many and diverse voices through a range of characters and narrators who can have different perspectives. The dialogue between the voices can become a complex and creative act just as it became in “A conversation with Jack and his family” (see above).

Drawing from the musical concept of polyphony, Russian literary theorist/critic and philosopher, Bakhtin (1984) termed the multi-voicedness in some novels as “polyphony” (p. 279). In his work on dialogism, he sought to explain the nature of such situations in literature, where independent but interconnected voices provide a diversity of views (Bakhtin, 1984, in Vice, 1997) often with attendant disagreement and conflict. Most importantly, “polyphony refers to the autonomy of the characters’ voices” (p. 112). The use of advice from a literary critic such as Bakhtin may seem far-fetched in consideration of health interactions. However, when we take note of the narrative function that physiotherapists may be assuming within clinical relationships developed in community settings, Bakhtin’s thoughts on dialogism assist to highlight the importance of on-going integration of the voice of others in the therapeutic narrative being heard and built with clients, families and carers. As community-based healthcare practitioners, therapists try to respect clients’ autonomy in healthcare processes as part of a person-centred approach to practice but have to deal with the polyphony of all the participants within client/family situations.

Jack’s individuality and autonomy can be seen with his family conversation (see above), “There’s a right way and a wrong way but Jack found his way”. Jack’s mother and carer promoted his autonomy through the vehicle of the conversation held. They became dialogic narrators in an effort to enhance Jack’s voice, creating a more relationship-centred approach.

**The Generation of Multiple Voices in Care-giving**

As well as considering the voices of different people who may be involved in community-based healthcare situations, the concept of polyphony can also apply to the various roles that one person may need to assume as a caregiver. The “multiple voices generated in care-giving” (Dobbins, 2009, p. 21) require negotiation. Dobbins discusses the different voices that may occur during home-based caring and proposed that there is,
… not the single, prototypical voice, but rather a negotiation of multiple voices generated through care-giving. People don’t just pick a voice and stick with it. They live through a kind of polyphony, or multi-voicedness … (There may be multiple voices in greater or lesser harmony. But all voices are present: all voices are part of the chorus of experience).

“Nested Narratives”: Multi-voicedness in Family Settings

Multi-voicedness has also been considered in family-based therapy, where Gergen and Gergen (1983) proposed the concept of “nested narratives” in family situations; a micro-narrative can be nested within a macro-narrative (p. 263). This term refers to the structuring of one person’s story within larger or broader family and societal narratives and could certainly be applied to the situation in which people find themselves in home-based healthcare. Although this is a useful way to view situations with many stories within a larger story, it assumes that such stories are already well formed. I consider that my term, “patched narratives” better articulates the composite and polylogical complexity of a family’s relationship with their community-based physiotherapist.

BEING PRESENT TO HEAR ALL THE VOICES

Karen’s interaction with Jack and his family in There’s a right way and a wrong way and Jack’s way subtly acknowledged Jack’s need to be heard. He was then able to make his presence felt through his sense of humour. Karen’s professional insight into the actual state of affairs occurring with his standing (where he had tricked his carers into thinking he was doing all the effort of standing) also served to enhance Jack’s individuality and sense of self. In a Bakhtinian sense, by stepping back to make sense of the moment and appreciating another’s point of view (White, 2009), Karen was able to validate Jack within the therapy process or contribute value to him. Bakhtin (1990) describes this process of stepping back from the dialogue as an “excess of seeing” (p. ix). Seeing from another person’s point of view and incorporating that view into the interaction assigns value to them.

From within the field of family and network therapy, Seikkula (2008) argued that what was needed was “to be present and to guarantee that all voices become heard” (p. 480). I would argue that community-based physiotherapists need to also add to this function of “hearing all voices” to actively incorporating those voices into the healthcare narratives that are being developed. Such dialogue between healthcare professionals, clients and caregivers is important in a broader sense as well. By caring for and about them and seeking to advocate for an improved quality of a client’s everyday life, healthcare professionals can assist with the presentation of a coherent story for that person within their family and community.
SENSITIVITY TO THE POETIC WITHIN CONVERSATION

The process of analysing the data within this research was made easier for me as a researcher by the recognition that strong messages were being sent from the participants within the research conversations through the use of words and phrases. When reading the transcripts, I searched for phrases with meaning to use as themes and as quotes, to explain concepts arising from the data. In many instances, poetic resonance was the means by which I was able to identify meaning. Other instances also occurred where participants used metaphor to explain to me the importance of their relationship with their physiotherapist. For example, Joanne explained, “Now I know where I stand”. She was not just talking about the difficulty she had physically balancing in standing but rather where she now felt placed in her rehabilitation journey.

When listening within the conversations we need to have with clients, practitioners with experience develop “an ear” for what is of most importance to clients. Enhanced sensitivity to poetic resonance heard within clinical conversation may open up greater understanding and aid the development of empathy and action between practitioners, their clients and clients’ families and carers. This can then assist them to better develop plans for good outcomes for that person, not just from a medical sense but also from a personal and social sense. I continued practising as a community-based physiotherapist while I was conducting my doctoral research project and had the opportunity to reflect in practice about this issue of sensitivity to poetic resonance in conversation. I observed that it seemed easier to notice phrases of importance to clients when they were emotionally engaged in the message they were trying to tell you as their practitioner. The following example occurred within a community group I was attending as a consulting physiotherapist:

I was getting a cup of coffee in the playgroup kitchen when a young mother came in. She looked stressed so I asked her if I could make her a coffee too. While we were waiting for the water to boil, she told me that she and her husband had been down at a city hospital with their little boy that week as he underwent a battery of tests and consultations. It had been very tiring and distressing, as they had been given the diagnosis of autism for him. She listed the people they had seen and what her understanding of the diagnosis was but then she stopped. Her face twisted and she said,

But he’s still my little boy.

We both stopped talking for a little while as the import of what she had just said hit us both. Then we resumed talking about how he was and what they were going to do now in the playgroup. As I handed her coffee to her, I said that perhaps we had better go out into the outside play area where her little boy was playing with one of the other workers. I repeated to her what she had said to me, “He is still your little boy”. She turned back and smiled,

He is isn’t he?
I realised that she had been able to communicate something very important to her and validating her feelings had given her relief. I was glad I had heard her properly. It can be difficult to know, as practitioners, whether we have always understood our clients well. Being able to hear them clearly is part of that process and I argue, can be enhanced by our recognition of poetic resonance in the words they speak to us.

CONCLUSION

The presentation of the transcripts from this research study in free verse gives us the opportunity to more fully enter the world of each participating client’s relationship with their physiotherapist and better understand the nature of that interaction. It was important to present these stories first, before further thematic analysis in this research, in order to better locate the study within its context. Such mindfulness enabled further consideration of those relationships, before I proceeded with the interpretation of research themes from the data and the development of a model of practice, *Mindful dialogues in community-based physiotherapy*, which will be discussed in the next chapter.

“Poetic phrases within conversation can crystallise meaning and poetry often has the capacity to penetrate experience more deeply than ordinary prose” (Furman, 2006, p. 561). The distillation of meaning experienced in a poetic phrase, spoken or written, can seep into our consciousness and stay there for further reflection (Tasker, 2014, p. 6-7). Such “waiting” for meaning to become clear was useful for this research study but I would also argue that practitioners may also benefit from sensitising themselves to the poetic resonance to be found within their clients’ conversation.

ACKNOWLEDGMENTS

The voices in this chapter come from participants, their families, their carers and their physiotherapists who took part in my doctoral research study, “Mindful dialogues in community-based physiotherapy” (2013). They gave of their time and energy for this project and their messages are clear in the poetry of their voices.

REFERENCES


Diane Tasker PhD
Education, Practice and Employability Network, Australia
5. A MODEL FOR MINDFUL DIALOGUES
IN COMMUNITY-BASED PRACTICE

This book is built around a research project that was Diane Tasker’s doctoral research, supervised by Stephen Loftus and Joy Higgs. Other chapters provide: the background for this research (Chapter 1), the research methodology (Chapter 2) and research findings ( Chapters 3 and 4). This chapter presents the main research product: A Mindful Dialogues Model of community-based practice. The research focused on physiotherapy practice since this was Diane’s field of practice and she brought a wealth of experience as well as excellent opportunities to engage with research participants. Physiotherapy was also a good arena for this study since this is a practice arena where the focus of community-based healthcare (rehabilitation and enhancing the quality of life for people with chronic disabilities) is a core practice category of physiotherapy and where physiotherapy practitioners spend considerable time with their patients, both during each visit and over time. So the key phenomena studied in the research (patient/practitioner relationships, practice models/approaches and ways of being and engaging in practice) could be studied in depth. Physiotherapy is not the only profession where such practice and setting links apply. We encourage readers to think of physiotherapy practice within community-based healthcare as the selected context for this research but not as the focus of the study – which is about producing sustainable and productive healthcare relationships with clients, families and carers in community-based healthcare. The Mindful Dialogues Model presented here is a vehicle for practitioners across the professions to reflect on their practice, and for educators to reflect on how they prepare health professionals to work well with their clients/patients in community-based healthcare. It is also a frame for researchers to explore the phenomenon of such healthcare and its setting as a place for mindful dialogues that facilitate the empowerment of clients/patients with chronic disabilities to co-construct optimal life-quality improvement rather than limiting healthcare to medical intervention and support.

CREATING MINDFUL DIALOGICAL RELATIONSHIPS:
A MODEL FOR PRACTICE

The Mindful Dialogues Model of community-based practice provides a framework for thinking about and planning the way community-based practitioners can develop sustainable and productive therapeutic relationships with clients, families and carers (see Figure 5.1). The thoughtful social interaction discussed by participants in this research provided opportunities for practitioners to better
explore, contextualise and facilitate healthcare for their clients. While the research was conducted with physiotherapists and does not claim to be representative of other professions, the following discussion is presented using discipline non-specific terms to prompt readers to reflect on the applicability of the model for additional professions and for others involved in healthcare in community-based settings.

Findings from this research identified three core elements of mindful dialogues, namely being mindful, staying engaged and being responsive. These elements interact in an ongoing and dynamic process as depicted by the intersecting angled sections of the icon in the centre of the diagram. These elements of care depend on the many ways that practitioners develop their therapeutic relationships. Each relationship is resourced by the people involved, the practitioners, clients, families and carers and is informed by the
practitioners’ knowledge and experience. Looking inside each of these three elements (see the three shaded areas) we see many dimensions that the research participants reported as part of their experiences and actions of being engaged in mindful dialogues.

Drawing these three elements of mindful, dialogical relationships together was a fourth integrative element: the practice of valuing different participants’ narratives and utilising narratives to interpret and create such relationships.

ELEMENT 1: BEING MINDFUL

Being mindful in the model refers to therapists’ relationship approaches. Central to a mindful approach is an embodied awareness of the particular context, experience and wishes of clients, families and carers across all aspects of community-based healthcare practice. Being mindful involved blending together, understanding (mindfulness) and (mindful) actions that embodied the therapists’ understanding of the patient’s (and family’s/carers’) narratives and situation. The various dimensions of being mindful identified in this study were:

- Understanding the nature of home-based healthcare, recognising this as hard work for clients, families and carers and understanding the impact of therapy on family situations
- being sensitive to the difficulties that families and carers face, including the realisation that progressive deterioration lies ahead for most
- recognising that home-based healthcare is an intrusion into family life
- realising that community-based therapeutic relationships need to evolve
- blending in with each family’s situation
- being conscious of the need for the therapists’ social and personal personas to be made available within the interactions
- allowing themselves to connect on an emotional level to better identify the meaning that people ascribe to their therapy interactions
- perceiving themselves as fellow travellers, on a journey with the people they come to assist.

Participating therapists in this research spoke of their need to be mindful of, and sensitive to, such human dimensions throughout their therapeutic relationships. When community-based therapists “come to call”, they are entering someone’s home, where they are a guest (Heckman & Cott, 2005). Community-based therapeutic relationships can only occur because of the hospitality of clients and their families who welcome and allow therapists into their homes and their lives. Past this initial hospitality process, acceptance and trust then needs to develop if successful therapy is to develop. Seeing and hearing how it really is for clients, families and carers is necessary before therapists try to suggest any possible actions and interventions. The embodied nature of such mindfulness incorporates (literally - as in the corporeal body) the way therapists need to be sensitive in all their dealings with the people they have come to assist. For therapist participants in the study this sensitivity had become a part of who and what they were as people. Mindfulness is also integral to the entire clinical encounter including the physical therapeutic activities as well as relationships. Although this thesis did not
attempt to directly examine the physical side of therapeutic interaction, it is clear that successful therapeutic relationships involve more than just talking with and more than just moving and touching clients during therapy interactions.

The success of community-based healthcare interactions depends on the ability or willingness of clients, families and carers to work with their healthcare professionals and for everyone concerned to understand that community-based healthcare is changeable and ongoing. Practitioners in this study recognised that their transitory presence in clients’ lives and their ability to participate or influence events for their client was inevitably piecemeal. Engagement with everyone concerned with clients’ care was necessary for these therapists to successfully negotiate the different contexts and individual experiences within the changing human and health situations they attended.

ELEMENT 2: STAYING ENGAGED

The therapists in the study demonstrated and reported the importance of staying engaged and connected with clients, families and carers by listening, talking and learning with the various people involved for each client. The therapists reported that getting comfortable with people is a necessary prerequisite if trust and confidence is to develop while encouraging clients, families and carers to share stories is an important means of building that trust. The various dimensions of staying engaged, identified in this study were:

- building trust within the relationship
- becoming comfortable with clients, families and carers
- talking with the people they had come to help
- listening and learning from clients, families and carers.

Participants observed that such stories are usually based on illness experiences, rather than just “the facts of the case”.

The help I want is not a matter of answering questions but of witnessing attempts to live in certain ways. I do not want my questions answered, I want my experiences shared. (Frank, 2002, pp. 13-14)

The research showed that opportunities exist for clients and/or families to tell therapists of their experiences and these opportunities can be enhanced if therapists are able to stay fully and sensitively engaged with clients, so that difficult issues can be freely expressed. All participants in clinical encounters want to be heard but the medical “voice” can sometimes seem louder and more dominant (Frank, 2002).

It was clear that the therapists in this study working in community-based healthcare settings respected the voices of the people they came to assist and recognised that balance is needed if everyone’s voice is to be heard. Relationships based on good engagement offer opportunities for such balance to develop.

Previous research (Ek, 1990) showed that the healthcare processes occur “moment to moment in real-time” (p. 2) and are reciprocal in nature, allowing both therapists and clients to learn and change. Iversen, Øien and Råheim (2008) argued that children with
cerebral palsy receiving therapy at school experienced deeper meaning and improved quality of movement through mutual creation of meaning through the communication with their therapists. This reinforces findings from this research that possibilities for substantive change can only occur through ongoing engagement between therapists, clients, families, and carers.

It can be difficult to stay engaged with people who are stuck in chaos narratives; “living a life of overwhelming trouble and suffering” and feeling that “life is never going to get better” (Frank, 1995, p. 113). The voice of the client can seem lost in chaos and even experienced therapists may feel the chasm of the other’s despair yawning at their feet. It is tempting for therapists to simply try “to fix things” with evidence-based techniques and activities and ignore what clients are feeling, but in the settings typical of this project, wise and experienced therapists sought a balance between the voice of medical science and the sensitivities of those they were caring for. The research findings revealed this sense of “the edge of despair” that can be felt in Joanne’s narrative I know now where I stand as she struggled to come to terms with the difficulty of her walking.

Sometimes balance between these voices of medicine (the biomedical, illness narrative) and life (including the wellness narrative) will include a combination of physical activity and relationship activities, acting together as a framework for clients and/or families and carers to move forward. Examples of this can clearly be seen in the relationships between Eric and Barbara, his physiotherapist, and between Dennis and his physiotherapist, Adam, in the description of their assisted walking activities. Opportunities for real dialogue can be facilitated by the inevitable touch and physical proximity that occurs within physiotherapy sessions and therapists commonly become aware of the power of this aspect of their interaction with clients. While it is beyond the scope of this research to deal in more depth with this haptic (touch) aspect of relationships in physiotherapy, its influence and presence must be sensitively acknowledged and incorporated within all the processes of being mindful, staying engaged, and being responsive.

**ELEMENT 3: BEING RESPONSIVE**

Truth is not born nor is it to be found inside the head of an individual person, it is born between people collectively searching for truth, in the process of their dialogic interaction. (Bakhtin, 1984, p. 110)

The need for therapists to be responsive within the relationships they dialogically build with clients, families, and carers is essential. The word, “responsive” can be used within healthcare discourses in different ways. In this project, regarding the creation of mindful dialogues, its use does not refer to “responding to an issue” but rather indicates a state and attitude of responsiveness, enabling a deepening of the interpersonal therapeutic relationship that develops in community-based healthcare. Such deepening is dialogical in the sense that all parties to the relationship contribute to it, being sensitive to how the other participants perceive the relationship and what they contribute to it. The various dimensions of being responsive identified in this study were:
being open
becoming emotionally attuned
interpreting and advocating clients’ wellbeing
caring for the carers
helping clients, families and carers take “baby steps” to the future
being friendly.

While the ability of some clients to contribute much to therapeutic relationships can be limited, it is crucial that therapists respond sensitively in all cases. *Being responsive* also relies on the characteristics of being mindful and staying engaged. In the findings from this research, achieving adequate responsiveness was dependent on the therapists’ experience and ability to combine their own inner reflective dialogue with dialoguing with clients, families and carers. By adopting an open attitude towards the other people, and demonstrating respect, the therapists were able to provide mentoring and guidance to clients, families and carers as they needed it. Their willingness to cope with ongoing complexity acknowledges that there can be no final solution to all the difficult issues being faced by clients, families and carers.

When community-based therapists leave their clients at the end of each visit, they inevitably leave them with their chronic and complex healthcare issues. While exploring therapy possibilities for clients with chronic and complex health difficulties, hope can still exist because of the ongoing nature of therapeutic relationships. Adam (Dennis’s therapist) commented,

> You always have to keep listening to what actually they are reporting to you, what their difficulties are and what they want to do and that then determines how you then change your program. (Adam)

*Being Responsive to Constantly Refresh One’s Insights*

The therapists’ ability to be responsive within clinical relationships allowed them to constantly refresh their insight into clients’ situations and increased the possibility of finding options for planning and evolving the therapy positively. Responsiveness tended to combine with trust building as relationships developed. This became apparent at many points in the project. Parallels of this idea can be seen in Gadamer’s (1975) terms: being aware of one’s own biases and prejudices in the attempt to be open to whatever the phenomenon reveals to you.

By adopting an open listening approach, which encourages the client or family to confide information about emotionally difficult topics, therapists provided opportunities for building trust, and at the same time, developed a more holistic impression of that person’s life world by a gradual “fusing of horizons” (Gadamer, 1975, p. 305). This term can be used to refer to the interaction that occurs between people in an effort to arrive at a shared meaning. Having an open approach allowed a deepening understanding of where the other is “coming from”, even in the face of disagreement. Such practice is hermeneutic with a melding of the parts, which includes the casual conversations, and the whole being the clinical relationship.
Drawing on Gadamer’s ideas, Todres (2008) described this deepening understanding as “embodied relational understanding”. Gradual and increasing understanding provides **constant refreshment of one’s insight**, incorporating a necessary openness to the “otherness” of particular phenomena. In conversational exchanges between people, the active listening of each voice from the perspective of the other becomes an opportunity to test our own and the other’s ideas in order to determine how we should act and how we should proceed (Zappen, 2000). The experienced therapists in this study demonstrated this ability to constantly refresh their insight.

**ELEMENT 4: USING NARRATIVES**

The research findings showed that the development of *mindfulness, engagement and responsiveness* relies on a narrative style of interaction for therapists in community-based practice. Even though health practitioners from all disciplines listen to the stories that their clients, families and carers tell them to make sense and meaning of a client’s situation it was clear that in the home-based settings of the study such narrative skills appeared to be highly developed. Clients and families, in their turn, rely on healthcare practitioners’ narrative skills to help them make sense of their lives and develop a manageable life story with which to continue.

In today’s healthcare, strict accountability and time constraints can get in the way of the therapist’s professional judgement and the way they work. A narrative approach (as seen in the *Mindful Dialogues Model*) can help us understand how therapists construct stories for their clients that allow integration of therapists’ craft and expertise with evidence-based practice and the abilities and wishes of clients and families.

*Multi-voiced Conversations*

This model refers to community-based therapeutic relationships where at least two people are engaged in these dialogues (and, at times, multi-voiced conversations or “polylogues”). The research focused on the practitioners and how they can be mindful, engaged and responsive so that they can foster constructive and effective interpersonal relationships that fully respect their clients. This does not preclude the idea of clients or families also facilitating engagement and dialogues and shaping the relationships. Indeed, this was the case for a number of client and family participants.

As part of this narrative exercise, community-based therapists liaise and communicate with many people as mentioned above and these *multi-voiced conversations* require sensitive, mindful care and negotiation, if the wellbeing of the client is to be promoted. Therapists often need to act as a *narrator* in such conversations as they sometimes *patch the narrative* to advocate for and engage with others (clients, family and carers) providing flow and momentum to therapy through those narratives.

In situations where clients have decreased abilities to communicate independently, families and carers will also use multi-voiced conversations to include clients in the social activities of conversation within therapy. Therapists then become a part of family conversations and stories. Therapy activities in these community settings intertwine
with meaningful human relationships for clients. Therapy interactions can also serve to model care to carers, thereby advocating for clients, carers or family members.

The Role of Asking Questions

In order to construct a narrative with which to begin to make sense of clients’ situations from a therapy point of view, therapists inevitably ask questions of clients, families and carers. Such questioning is usually taken for granted as part of a professional interaction. This research considered the nature and role of dialogue both in the study and in the practice of community-based therapy. A model of question asking from the field of management inquiry called appreciative inquiry could prove useful for further studies. This philosophy of change originated with the work of Cooperrider and Srivastva (1987), which used dialogism within a social constructionist framing of inquiry to interact with organisations, helping them to change and develop. “Appreciative inquiry focuses on ‘when things worked well’, encouraging a solution-focused discussion to explore how individuals can do more of what works rather than less of what does not” (Jones et al., 2009, p. 31).

Community-based therapists are not only looking for deficits to assist with but for positives to build on, helping clients to have a more balanced view of their lives. The narratives they devise with clients reflect such balance. This particular way of using questions comes from the area of systems management but its possible use for the more specific area of interpersonal interaction could provide a fruitful avenue for future research.

IMPLICATIONS FOR PRACTICE

Practitioners need to engage with all aspects of the model if they want to provide good care. Importantly, many activities need to be harmonised and frequently adjusted. An example of this adjustment can be seen in the instances where practitioners discover some new aspect of the situation that they were not aware of before. Such opportunities for reflection can provide deep insight for healthcare professionals and motivate them to continue in their efforts to relate to clients, families and carers. Reflection and ongoing engagement with these clients helped to open up a relational space where therapists could sustain and deepen their understanding of different people in different situations.

Practitioners can use this model when reflecting on their practice generally or more specifically, when preparing for a particular client’s therapy. The Mindful Dialogues Model can be used in practice to frame discussion about different clinical topics. For example, this practice model has now been used to frame discussion regarding communication for safety in healthcare for people with limited communication abilities (De Bortoli & Tasker, 2013). Many possible approaches to the healthcare situations of specific clients could then be deeply and richly explored, providing truly contextualised and relationship-centred healthcare for those people.
Enabling and Sustaining Mindful Embodied Dialogues in Practice

An implication of utilising mindful, embodied dialogues in community-based healthcare is that practitioners generally should be more reflective. There is value in stopping to raise their heads above their busy work lives, to look around them, and consider how they enact and frame their practice. Therapists have a reputation among themselves and among other health professionals as being “heads down, tails up”, working hard. Findings from this research can encourage other therapists to adjust that “busyness” tendency, to create a more mindful balance between action and reflection in their practice.

The need to “raise one’s head above a busy work life” was identified by Adam, one of the therapist participants as an important issue. Adam had been sensitive to his lack of knowledge and experience in human relationship matters, both as a student and later as a practising therapist and wondered why this subject was not brought up for more attention in undergraduate education and ongoing professional development activities. One aspect of this need for reflection was the ability to decide on and negotiate boundaries.

Negotiating Personal and Professional Boundaries within the Therapeutic Relationship is Difficult for all Parties

Negotiating boundaries between personal and professional aspects of the therapeutic relationship can be a difficult, anxious and ongoing process for everyone concerned (despite the goodwill of most parties). At the same time, negotiation of boundaries is also an important way for therapists, clients, families and carers to become comfortable with each other and manage the intrusion and inconvenience felt by clients and families who are being visited in their own home by healthcare professionals. A curious paradox also exists in the convenience of being visited in your own home when energy and time are at a premium. The careful presentation of both the personal and professional personas of the therapist seemed to assist in bridging these issues with people. Despite the anxiety felt by some of the therapist participants about this issue, the findings suggested that therapists found the relationships they developed with clients and their families to be rewarding.

I’m certainly there as the physio but I want to relate on a much friendlier sort of level, I think.

I find they end up calling me their friend or part of their family as well, which is a great compliment. That is a gift. (Comments from Barbara, Eric’s therapist)

The resourcing of participating therapists’ care and effort could be achieved by their accessing the human aspects of the clinical relationship they sought to develop. The different elements within the Mindful Dialogues Model can encourage healthcare professionals to consciously develop a coherent and manageable way of developing sound relationships and framing the boundaries within their professional practice in a manner which will meet the needs of their clients and themselves.
Resourcing Mindful Dialogical Relationships in Practice

The human and social qualities of practitioners, clients, families and carers can become resources for the therapeutic relationship being developed. Such resourcing can help to balance the flow of effort from and to the therapist involved. In this research, motivation for the therapists appeared to come from different sources, the therapists themselves (while being mindful), community members with whom they interacted (while staying engaged), their own professional training and experience (allowing responsiveness) and appreciating others’ narratives.

Being mindful draws on the personal resources of the therapists themselves, who need to take care of and accept responsibility for the developing human relationships between clients, families and carers and themselves. Therapists need to think about and notice aspects of the therapy situation, taking into account and accepting the varying presentations and wishes of the different people involved. The Mindful Dialogues Model establishes a common ground of contact upon which the people concerned in community-based healthcare situations can build ongoing interaction. The need for common ground was also highlighted by Iversen et al. (2008), although their study was with children rather than adults.

Staying engaged acknowledges the difficulty of staying alert to other people’s concerns and maintaining connection with the people the therapists are trying to help. As therapists strive to stay engaged with the people they come to assist, they rely on conversation with those people for topics with which to frame ongoing interaction. As John (Jenny’s therapist) said, “I think it’s listening to what the subject is and how you can make that connection too”. Resources for this part of the relationship can therefore be sought from the people with whom practitioners interact. Such dialogue can form the content and provide motivation for the conversation needed to maintain interpersonal connection between therapists, clients, families and carers.

Being responsive encourages practitioners to maintain an open, receptive approach, allowing all concerned parties within the relationship to keep options open for future possibilities. In many situations, these future possibilities will be driven primarily by the knowledge and expertise of the health professional concerned but would also take into account the ideas and experience of everyone concerned. By incorporating the clients’ ideas and perceptions, therapists highlight and enhance the identity of all the people they come to assist.

Enacting Mindful Community-based Healthcare Relationships

This research revealed community-based healthcare practice as a complex and dynamic phenomenon. While therapy can enhance patients’ health (particularly mobility and daily activities), its physical benefits were only part of what was needed for clients to be able to achieve a greater sense of wellbeing. Considerable effort was needed by therapists and other people involved in home-based healthcare to help clients fully benefit from therapy. Clients, family members and carers all have a critical role in community-based healthcare twenty-four hours a day, not just while the therapist is “in the house”. Therapists cannot just visit, carry out 30-60 minutes of purely physical therapy and expect positive outcomes. Such complex life and health situations as these
clients experienced need something more than therapy. Rather, collaboration in the form of relationship building, shared care/therapy and collaboration in planning therapy that is integrated into people’s lives needs to occur between therapists, clients, family and carers, created within human relationships for the good of the client concerned.

Collaborating within Human Relationships

People live within relationships and these relationships provide the context for the interactions that clients have with healthcare workers. This research showed that attending therapists needed to be mindful of this context and engage in a dialogical process that can build relationships while at the same time enabling clients and carers to participate in how therapy was to be framed and implemented. When therapeutic relationships (and therapy) were working well it was because the therapists, clients and carers were collaborating together. Mindfulness was identified as a vital key to the success of interactions in such therapeutic collaboration. Such a relationship must not be a manipulative means of achieving compliance; it is a respectful vehicle for collaboration. Mindful relationships are essential for success in this form of therapy. Relational success here is seen as part of the optimal outcome for the wellbeing of clients, families and carers This can be applied to practice by therapists routinely reflecting on how well they are managing to “stay in touch” with clients and families and how easily other participants in the relationships are able to articulate their needs and wishes.

Integrating Evidence-based Practice with Human Needs

People with chronic and complex health issues face great uncertainty and depend on healthcare practitioners to help guide them towards improved wellbeing and at least some mitigation of that uncertainty. Such guidance ideally does not spring just from the therapists’ professional knowledge and experience, it is also informed by the narratives of the clients and carers: it is a responsive endeavour. The therapists in the study had to work towards this improved wellbeing in a world dominated by evidence-based practice. Evidenced-based practice in healthcare seeks best health outcomes for clients by adopting treatment founded exclusively on the scientific research method.

A major problem with this approach is that the scientific research-derived evidence can be based on artificial, acontextual experiments that may not be relevant to the complex clinical situations that many therapists and their clients have to confront, such as those in the study. Healthcare based strictly on such evidence-based practice aims for certainty but complex situations cannot, by their nature, always be predictable. The unpredictability of real life situations requires interpretation, a great degree of flexibility, of collaboration, and of attention to the particular. Such an approach requires therapists to develop a rich understanding of the context and complexity of chronic care and home-based care, to generate and test their practice-based knowledge as a complementary source of evidence for practice alongside research-generated knowledge and an appreciation of the role of people’s (therapists’, clients’, carers’)
narratives in shaping, modifying and realising successful, individualised and holistic healthcare practices and outcomes.

One aspect of this collaboration is that people “on their own turf” may not always agree with all aspects of the advice given to them (even if it is evidence-based) when working with their visiting practitioners. Findings from this research generally indicated that clients and their families felt more empowered in their own homes to change their mind when and how they liked, show mood changes and generally behave like the real people they were. A good example of this could be seen when Jack decided to leave the research conversation and depart into another room. Such personal agency contrasts with the more apprehensive and disempowered position that patients within an institutional setting can often feel, where they can be under pressure to “toe the line” of that institution.

This means that for therapists, such as those in the study, the challenge in community-based healthcare is to integrate their practice-based evidence with research-based evidence – combining both of these sources of evidence - and, just as importantly, to incorporate the narratives and wishes of clients and families.

If we are to follow Sackett et al.’s injunction to integrate individual expertise with the best available evidence, we will need a means of talking about how to do so. A dialogical approach gives us permission to explore, critique and synthesise ideas so that we can talk about clinical reasoning in new and more meaningful ways. (Loftus, 2012, p. 1174)

This integration did occur in the settings of this study. Indeed, the talking referred to in this quote occurred between the people involved in the therapy activity as they negotiated what they wanted from the clinical encounter. The findings show that this negotiation is best understood as a dialogical process within the relational space created by therapists within the therapy situation. The required negotiation means that practitioners in these settings have to listen to and consider the voices of many different people and must widen their perspectives on what they pay attention to in therapeutic interactions.

A key issue related to this research is that therapist participants were experienced practitioners. Their success was due to the richness of their practice experience. Their underlying awareness of the value of narratives and dialogues derived from their reflections on practice and their chosen work context and practice models. For therapists new to community-based healthcare and to chronic care, such narratives and experiential knowledge are likely to be missing or in early development. Therapists need to develop their narrative and dialogical abilities for this form of practice.

Reflection, aided by talking with other practitioners, needs to include the what, why, when, where, who and how of practice. These are narrative skills. It became obvious in the focus group, which was conducted with therapists for this research, that the therapists benefited from such discussion of the narrative and relational ways they practised their therapy. Talking with colleagues about work in relaxed conversations can be invaluable for practitioners at any level of expertise, for both personal and professional support, but especially in the early years. Such talk needs to be separate to clinical supervision although that avenue is of great value as well.
Listening to and Considering the Voices of Many Different People in Community-based Healthcare

When illness or disability is present for people living at home, significant help from other people is usually needed. Negotiation and collaboration must be sought from a variety of people if all viable healthcare and life capacity building options and choices are to be properly explored for clients and the efforts of the carers best supported. Clients can then engage with healthcare in a way that is acceptable to them and more likely to bring about desired outcomes.

Edwards, Jones, Higgs, Trede and Jensen (2004), in identifying different styles of knowledge exchange between therapists and their clients argued for a collaborative model of decision making in therapy, allowing for exploration of polarities within therapy processes. Their research supported that of Mattsson, Wikman, Dahlgren and Mattsson (2000) who proposed that therapists’ overall method of working could be viewed as “the art of adjusting” (p. 125).

Findings arising from this research also shed light on this “art of adjusting”. Therapists made careful efforts to engender goodwill and promote collaboration towards goals that were mutually agreed upon between practitioners, clients, carers and family members. Emphasis needs to be put on the term, “mutually agreed upon” because without that essential aspect of the clinical relationship and its outcomes, collaboration is just a buzzword for policy documents. The collaborative efforts of all the participants in this research were seen to be embodied within the relationships that developed between therapists, clients, families and carers. Therapy cannot really be successful without such collaboration, particularly as the actual physical movement work for clients needs to take place when the therapist is not there as well as when they are. Collaboration needs to be seen within practice as an ongoing activity. It is a difficult process, constantly demanding of therapists that they balance their professional views with their clients’ views and opinions. It requires therapists to stay within the space of the interpersonal relationship with clients, families and carers and avoid withdrawing into a purely technical relationship.

CONCLUSION

It is important to think about how we practise as well as what we practise. Such reflective thinking can have implications for ourselves as people as well as therapists, assisting us to develop satisfying work lives with our clients and their families. Creating productive relationships within home-based healthcare situations involves the use of our heads, hearts and hands. It is person-centred care. It is also relationship-centred care. Mindfulness, engagement and responsiveness are necessary components of community-based healthcare relationships. The practice model of Mindful Dialogues presented here promotes the building of sustainable relationships for community-based practitioners working with and for clients living at home with chronic and complex healthcare problems.
NOTE

Sackett, Richardson, Rosenberg, and Haynes (1996) argued that the best possible evidence needs to be combined with the clinician’s expertise together with the patient’s wants and desires.

REFERENCES


Diane Tasker PhD
Education, Practice and Employability Network, Australia

Joy Higgs AM PFHEA PhD
Education, Practice and Employability Network, Australia
SECTION 3

COMMUNITY-BASED HEALTHCARE:
LIVED EXPERIENCES
INTRODUCTION

The whole point of community-based healthcare (CBHC) is to assist people with healthcare problems to have the choice of living in their own home. In today’s society in Australia, it is now possible for that to happen for people with a wide range of bodily impairments or healthcare concerns, including for example, living with a ventilator, cognitive impairment or impaired mobility. As an example, first author, Mark, lives and works from home while dealing with multiple sclerosis, which has caused him to be wheelchair-bound.

In this chapter, he and his previous physiotherapist, Diane (co-author), explore some thematic issues involved in the way that clients can feel about their interaction with community-based health as a system and with the people they might meet along the way and put forward some suggestions as to how those relationships might better be envisioned for future care situations. A central message is the importance of developing good relationships between health professional and client over time.

LIVING WITH MY BODY – IN MY LIFE

Community-based healthcare clients often find that their days become dominated by issues to do with the management of their body. Medical appointments, the travel involved and all the minutiae of activities of daily living can often be more complex and take long periods of time to accomplish. In the following narrative, Mark explains how his morning unfolds before the day can truly begin for him.

If You are Going to Live in the Same World as Everyone Else who Works...

The biggest issues with getting ready in the morning are simple things like getting into the shower. I have to transfer into another shower chair with a slow, difficult, stand and turn process. Along with doing that, I also have to disconnect my urine bag and its tubing and carry everything with me into the bathroom. I then have to empty the overnight bag and draw up a disinfectant solution to wash the bag and tube (takes about 15 minutes). Going to the toilet needs an enema, time waiting for it to work (and then if it doesn’t work, you have to manually evacuate and clean up) (takes about 40 mins). Then showering, drying - if you are on your own, it is very tiring. Lifting limbs that won’t work is hard and tiring work. I can’t use big
towels. Then back to bedroom. Skin care is very important (takes about 20mins). A skin condition can take months to cure. Putting on my leg bag and dressing is challenging; if getting ready to go to work with more formal clothes, the whole process may take 2-3 hours. Sometimes I may need to rest after my shower before dressing. The nature of multiple sclerosis makes it different every day.

The thing is, if you are going to live in the same world as everyone else who works, you have to always allow enough time to be able to fit in with other people’s timetable and appointments. In their world they get up and get ready in 30-40 minutes. Not only does it take me 3-4 times as long, often when I am finished, I am exhausted … and my day hasn’t really started yet.

Reflection

The above narrative is told simply, indeed, maybe too simply. It doesn’t describe the spasming of limbs when trying to stand for transfers, the fight to remain seated on the side of the bed with poor trunk control, the loss of sensation in fingers when trying to dress oneself or the ever-present nerve pain which requires strong medication to allow sleep at night. Even if you just consider the issue that it takes Mark 3-4 times the time needed usually to dress, there is a great gap between the requirements for Mark to dress for work or for other people to get ready for work. What a way to start the day, every day.

The experience of disability for a client is therefore clearly a matter of the difficulties they experience in interacting with the world around them and with society, which is usually set up for the use of people without any bodily impairment. Much negotiation and organisation is required to achieve a meaningful and manageable life. Indeed the WHO (World Health Organization) clearly differentiates between the definition of impairments and disability.

Impairments – concerned with abnormalities of body structure and appearance and with organ or system function resulting from any cause; in principle, impairments represent disturbances at the organ level.

Disabilities – reflecting the consequences of impairment in terms of functional performance and activity by the individual; disabilities thus represent disturbances at the level of the person. (WHO, 1980, p. 14)

In a society which has patchy provision of disability access at best, a person’s home needs to be one place where their experience of disability could be minimised by careful accommodations made to both the physical and social environments involved. To make that happen, it is often necessary for other people to visit the home to assist with different aspects of such accommodations.

OTHER PEOPLE IN MY HOUSE

We all know what it feels like to come home and close the door on the world. The feeling of privacy that is felt within one’s home was referred to by one participant in the research study described earlier in this book (see Section 2) as “sacred
space”. Visitors to the home are guests and invited for set periods of time, usually at the wish of the homeowner. Indeed, Heckman and Cott (2005) propose that visiting practitioners should still be considered within this “guest” framework. We all know what it can feel like if visitors stay too long and the blissful feeling when they go. However, for clients of CBHC, these personal boundaries can become blurred. In the following narrative, Jenny describes how she feels when the community nurse comes to call unexpectedly.

What was the Whole Story?

I was just relaxing in bed with a cup of tea and the newspaper when I heard a banging on the locked gate outside. I couldn’t think what it was about but I hurried to get up and put my slippers on. My heart was thumping because I wasn’t expecting anyone. I was really surprised to see a lady outside, who I didn’t know. I felt a bit embarrassed because I was in my pyjamas and my hair wasn’t brushed. She said she was the nurse. I said that I didn’t know she was coming and she laughed and said that she had just popped in to see if I was ok. She was a very nice woman and spent a lot of time with me but I would have preferred to have had my cup of tea and read my paper. I felt quite flustered after the visit but I guess they have their rounds to do and I probably just have to fit in with that. Perhaps I had better not stay in bed so long in the morning.

Reflection

Clients may find themselves coping with a succession of various healthcare practitioners as a new way of living is worked out for them. This may then become a succession of visitors in the long term. The entrance of any practitioner into someone’s home is going to inevitably change the dynamics of a person’s day and sometimes even the day after that. For people with serious, ongoing healthcare concerns and/or disability, management of their time is important. Their time is not less valuable than that of anyone else. Indeed one could argue that it may be more valuable because, as we saw above, what time they have is hard won and may be limited. It may seem that the idea of community-based healthcare might ameliorate some of these issues but that does not always happen.

In the above narrative, Jenny did appreciate the pleasant friendliness of the nurses but it completely disrupted her day and indeed she was still tired the next day as well. She had felt quite “put on the spot” and her dignity was affected by being caught not yet dressed and ready. She said later that she hoped that the nurses hadn’t thought she wasn’t coping at home because she was doing very well really. The visit had taken well over an hour and so she had missed going to do her shopping as well.

Jenny felt quite unable to express any of these feelings to the nurses and so they would have been completely oblivious to the effect their visit has caused. The visiting nurse may well have thought that her visit had been appreciated by Jenny, and so it had, but that was not the whole story.
In the following narrative, Mark describes some of the difficulties he faced with the provision of one particular service – the changing of his catheter. Again, the whole story was not told to the visiting practitioner.

*I Want to Feel Safe and Comfortable*

The reality is when you have a disability or healthcare issue, you have to accept that things can’t be as they were but do they have to be quite so difficult? You would just get comfortable with one nurse and how to do the process for your body but, every three to six months, they would change the nurses to stop people feeling dependent on them. It’s really annoying to have to repeat communicating about the whole process to a constant stream of new people. To put it bluntly, all of a sudden, you have your pants down for a personal procedure with someone you have just met at the door five minutes before. You have no choice. You don't want to offend anyone and you know you have to have it done. You have to fit in. I get all that. Is it really that bad if I do feel comfortable with the nurse. I want to feel safe and comfortable. I can’t do that with a stranger. It is embarrassing and frustrating and very confronting. Some nurses try to go slowly to make me feel comfortable but I am beyond it by then. I just want to get to work.

*Reflection*

There is an increasing tendency within CBHC for guidelines, rules and regulations to be set up in workplaces and those workplaces are inevitably in the homes of clients. Very often, the initiative in this regard comes from the healthcare visitors and the organisations from which they come. For example, rostering of staff can cause many changes of practitioner for clients to cope with together with all the difficulties and complexities of communication that will follow. Occupational health and safety, particularly, can dominate negotiations between clients and visiting healthcare providers, especially at the start of any service provision. It is important for everyone’s wellbeing that occupational health and safety is considered but, from a client’s perspective, it can sometimes seem onerous and intrusive within the context of their home setting.

*MY HOUSE, MY HOME*

People need to make many accommodations in order to live at home with healthcare concerns or disability and they naturally work at making things work well for themselves. Home is their base and their security; a place where they need to feel safe and comfortable. Very often, CBHC services will need to be involved to assist after a return from hospital, after illness or injury or where there has been a change in physical status along the course of a chronic illness. For people who have grown up with a developmental disability, such changes may happen slowly and incrementally but for someone who has had a sudden change of health or ability, accommodations may need to happen quite quickly.
People work hard to make a home and have personal and private ideas of how they want to live. It can be very confronting to accept the idea of assistance or changes such as ramps, handrails or equipment in that home. Visiting healthcare practitioners need to develop a helpful, but not intrusive, relationship with clients so that they can work their way through such processes to achieve an outcome that is useful and acceptable to all concerned. Sometimes that will mean being flexible and trying things out until a client finds what works best for them, as some initial ideas may be rejected. In the following narrative, Jan needed to work through such issues in order to be able to continue living in her home independently, as her health deteriorated.

“I Might have Felt Just the Same if it was Me”

Jan lived on her own in the house she had shared for many years with her husband. After he died, she stayed there with the support of her family who lived nearby. She had friendly neighbours and enjoyed contact with them several times a week. She loved her home and was quite house-proud, rising early each morning to “do the house” before 10am morning tea, as she had done all her adult life. However, Jan had respiratory problems, which started to worsen over time. She started to feel breathless when lying flat in bed but found that using pillows to raise her head caused her lower back to ache. The community nurse suggested that a bed with an electric headrest might help and referred Jan to the local occupational therapist (OT).

However, when the therapist came to visit, Joan was reluctant to have what she perceived as hospital equipment in her house. It wouldn’t feel very homelike, she thought. After discussion, she agreed to try a foam bed wedge but it didn’t really “do the job” and she discarded it. She started to sleep in her electric recliner in the lounge room but her ankles started to swell up by morning time and her back continued to hurt. It all felt increasingly difficult. After another hospitalisation where Jan experienced the benefit of a hospital style bed with an electric backrest, the OT, who had kept in touch with her, visited again and brought some pictures of an electric bed with a “homestyle” wooden headboard. Jan thought it looked “quite nice” and agreed to a trial, which was successful. A similar process happened again with the need for bathroom handrails. Again, time was needed for Jan to think through what she needed and what she found acceptable in her home. “I know I have seemed a bit difficult,” she said to the OT. “Don’t worry, I think I might have felt just the same if it was me,” the OT replied.

**Thoughts for the Future**

People react and respond differently when they live in their own homes, in contrast to when they receive treatment in a clinical facility. Along with development of relational healthcare approaches, physical and infrastructural accommodations can also assist in the provision of CBHC. With the ever-
increasing population and in NSW, increasing house prices, there has been a return to multi-family residences where successive generations of the one family live together under the one roof. To encourage and support more affordable housing, local councils have promoted and allowed the idea of “granny flats” – usually one-level, ground level, adjoined to or separate from the main residence on the property. Such planning can help ease the introduction of assisted living for people as they grow older or when illness or injury occur. It also has implications for the provision of relational CBHC, with family being able to live closer to people needing extra assistance to live at home.

With the past emphasis on formal clinical settings for the provision of healthcare, it may be that practitioner training and education has not yet adapted to how other settings, such as the home, can impact an individual client. Mark wishes of practitioners that,

They need to be easy to talk to. I need them to be able to talk easily.

They want all the info from me but don't want me to know about them.

They are technically trained but not people trained, not real hands on experience of how to relate to people, moment to moment.

CONCLUSION

Home provides the context for CBHC and can also provide a way for people to relate to each other; one that can be adopted by visiting healthcare practitioners to truly enhance a client’s health and wellbeing. This chapter has opened the window a little into the ways that clients experience their interactions with CBHC practitioners. Of course, every client will have a different story. As a visiting healthcare practitioner, it will be up to you to find those stories out as you get to know your clients – we argue that how well you are able to do that will depend on your ability to relate to them.

REFERENCES


Mark Horton
Wagga Wagga, New South Wales, Australia

Diane Tasker PhD
Education, Practice and Employability Network, Australia
7. FAMILIES

People’s homes and the family members within them will inevitably be closely involved in any home-based healthcare that occurs there. Family members will be bound to a person who is receiving healthcare through ties of affection and concern but also through the effect such care has on their own lives. In many situations, it can take much determination, tolerance and invention, not to mention hard work to enable a person to continue living at home with significant health difficulties that can include a range of physical and/or cognitive impairments. Within a family, there may be some members who undertake most of the care needed but other family members, for example siblings and extended family, will inevitably need to be involved in some way.

Community-based health practitioners also see many older people living on their own at home. Sometimes they have family members in the background but there are also those who are truly alone and for whom other community members and the healthcare services fill the gap that family might otherwise fill. In this chapter, the authors discuss some important relational issues that can arise for families when engaged with community-based healthcare.

SETTING THE SCENE

Today, we are familiar with hospitals, medical clinics and nursing homes but, increasingly, families want and choose to look after their own family members at home. Governments too are aware of increasing populations who are getting older, have more chronic problems, and the consequent expanding cost of healthcare. In order to cope with post-injury rehabilitation and chronic illness, community-based healthcare (CBHC) offers a more economically sustainable healthcare system, while also encouraging families to remain living together.

Health issues for people living at home range from serious injury such as acquired brain injury or spinal cord injury to living with chronic health problems or physical and cognitive impairment, such as dementia, stroke or developmental delay. The reasons why families choose to care for their family members at home when healthcare problems arise vary widely and can be complex. However, it also needs to be acknowledged that not all families or family members will be able to, or want, to live their lives caring full time for another family member. Even when there is much love, it can be a very hard road to travel and there may be many considerations that will impact on the decision to care for a family member at home. People also may not have a home to live in or be in a transitory situation...
regarding their housing. In this chapter we acknowledge these people and also consider families who can and do want to care for their relatives at home.

WHEN NEED FOR HELP OUTWEIGHS THE SENSE OF INTRUSION

Coming to grips with a severe healthcare issue and trying to live at home despite it, takes time and effort and can feel overwhelming at first. There can be a sense of chaos in a household before systems of care are sorted out or when a health crisis occurs. Peter came home from hospital after a spinal cord injury. His nurse, Jackie remembers that time. She shared:

Peter, do you remember how busy things were when you first came home? All the family was at home at that time; your sister was still at school and it was a very busy normal family household of six. It was a lot of work and effort trying to get everything sorted out and settling in. It is so much quieter and organised now after all the time that has passed and the work that has been done by everyone. (Tasker & Jones, 2014, p. 129)

Peter adds,

It was especially difficult for my family having people intrude into their personal space and even more difficult for Mum. She is very house-proud and likes her home kept in a certain way. Carers don’t mean to but they do move things around and put things in the wrong place. That is frustrating for everyone. Nothing is nurse-proof and if it can be broken, it will be. Home-based healthcare is an intrusion into family life, no matter how needed or wanted it is. The way we communicate with each other helps to ease that sense of intrusion. (Tasker & Jones, 2014, p. 129)

In most families, there are established dynamics, with roles and responsibilities mostly sorted out within a family. The balance of these can, however, be disturbed with people coming in to help or advise. This can be complicated if CBHC practitioners only get to see one member of the family when they visit. Other family members may want to be involved but are unable to do so because of work commitments that may not fit with CBHC working hours. The passing on of information given by CBHC staff may also inadvertently be altered when it is passed on between family members. This issue can be exacerbated if family do not live where a client does and also where there may be issues of memory (for example with a client who is suffering dementia or memory problems).

Wanting to manage but not being sure of how to do everything that is required, can lead to excessive fatigue and mistakes, such as increasing falls, medication mistakes, and tension between family members who are trying to carry on normal patterns of living, work and family care whilst meeting the needs of a family member with extra healthcare needs. It is difficult to have healthcare visitors coming to your house. There can be a feeling of being managed, even with careful, kind practitioners. As Peter said above,
Home-based healthcare is an intrusion into family life, no matter how needed or wanted it is. (Tasker & Jones, 2014, p. 129)

The following narrative involves two families who live in the same house with CBHC services visiting the parental couple downstairs.

*Needing Help but Not Being Able to Ask For It*

John and Mary were a couple in their seventies who lived in a flat downstairs from their daughter, Natalie and her family. Mary had dementia and severe arthritis and John depended on Natalie for help caring for her even though he liked to do as much as he could himself. CBHC staff had arranged a visit with John and Mary to discuss how they might assist and what services could be offered. Because John and Mary lived in the downstairs flat quite autonomously from their family upstairs, Natalie didn’t like to intrude on the appointment. However, as the meeting continued, John realised that some of the decisions being made involved changes to the house (in the form of rails). He asked Natalie to join them.

As they then continued to talk, all together, Natalie realised that John had not talked to the nurse about issues to do with Mary’s continence and their difficulty managing the large amounts of washing this was generating. She realised that he may be trying to protect Mary’s privacy, perhaps fearful that if he wasn’t seen to be coping, someone might suggest that Mary needed to go into a nursing home. In this first meeting, they all agreed to go ahead with a referral to get some handrails installed. Natalie decided not to raise other sensitive issues in this first session and to have some further conversation about them with her dad. The visiting nurse also realised during the conversation that there were more concerns for the family than were being discussed. Based on her experience, she did not probe further and organised another visit for a week later.

Over a few visits, with support and conversation between Natalie and her parents in between visits, several difficult issues such as falls, continence and Mary’s tendency to wander a lot in the late afternoons (known as “sun-downing”) were gradually disclosed and appropriate assistance was provided. John developed some trust in the process. This was due in part to Natalie’s reassurance that she and her family were clear and positive about John and Mary living with them, and also that they were determined to deal with each problem as it came along. John became more relaxed with each visit. He finally accepted some homecare assistance with laundry and housecleaning to manage his energy while caring for Mary. Mary herself was more positive about the visits, seeing these as a way to help John. She also enjoyed the social interactions entailed by the visits.

*Reflection*

Everyone in a household will have something to contribute, however not everyone will necessarily be present to interact with a visiting practitioner. This may also occur with medical appointments, but can seem more important when healthcare is
taken into the family home. When supporting a family to meet healthcare needs at home, CBHC practitioners need to be sensitively aware of this issue and the needs of other family members. A particular example of sensitivity to other family members includes the presence of children. Very often, CBHC visits will occur when children are at school. At other times, however, children may be present and may be very interested or not wanting to be involved at all. In the presence of children, practitioners will need to proceed with gentle interaction when it seems wanted as well as respect for personal space (which may be different when being in someone’s home).

Developing comfort in interactions and building trust can help people overcome the difficulty they may feel with the intrusion of healthcare into their family life. This may involve a gentle and delicate process that cannot usually happen in one visit. CBHC practitioners who are skilled at listening and fitting in can better tailor the help they give so that care for a client develops in an easy and comfortable way, which reassures all members of the family.

FAMILIES CARRY THEIR STORY IN NETWORKS OF RELATIONSHIP

I had to be his voice.
He didn't ask to be born and didn't have a choice.
I had to be his voice.
He had no choice and was totally vulnerable.

When you have a child with a disability, you are so aware of their vulnerability. You have to keep them safe.
You know him best.

All families have a life together and a history, which is uniquely their own. It is not easy for a visitor with limited time to ascertain this and how it may affect and assist the giving of advice and assistance. While every one develops their own life story, families do too. Nowhere is this more evident than in families who have cared for loved ones over many years. Not only do they have experience in what has worked for them in the past but they will have very clear systems of care in place and there may be one family member in particular who communicates this to visiting CBHC practitioners.

New CBHC practitioners coming into this situation will need to try and fit into the existing scheme of things before they can introduce or propose any new ideas, the exception being when help has been specifically sought for a particular issue. Interwoven into such family scenes will be the presence of other healthcare practitioners, all of whom may need to interact with the family and possibly the new practitioner. Each of these practitioners will also carry their own story with its inherent biases and background, but also possibilities for connection with others. In the following piece, Catherine speaks of the networks of relationship that developed for her and her family as they cared for their son, Jonathan at home.
Tag teams, in a seamless way

The good ones know not to intrude.
They come seamlessly into your house and do what they can to help.
Not always experienced but always positive and helpful.
They don’t tell you what to do or whether your house is clean enough.
It’s very much a community thing
with me to the end (of my son’s life).
And the relationship continues – they become extended family.

If they only came once or twice there was no real relationship but when practitioners come for long periods of time, relationships and trust develop.
You can’t disguise compassion. Compassion and common sense are a bonus and give you ideal care for your vulnerable child.

If you have never been there, you cannot know how desperately alone you feel and how desperately you need support and help.
Desperation becomes survival – how do you know how to carry on for another 5, 10, 15 years.
He grew bigger, then couldn’t stand.
It’s meant lifting, hoisting someone bigger than myself.

Even today, they remember us.
I don’t remember them but they remember us.

SHARING EXPERIENCES TO BUILD TRUST

A visiting healthcare practitioner cannot know the background of family members they meet when they come to visit a client. A family member may have been a practitioner themselves. They may have had a recent bereavement or be illiterate and not able to read written instructions. They may originate from a different culture with English as a second language. The range of possibilities that may present are endless. Regardless of these differences and uncertainties, CBHC practitioners and the clients and families they are visiting, will already share an important common intention - for the wellbeing of the client and their family. It is essentially why they are there! The task then becomes to build on that common goal by nurturing a sufficiently strong relationship that includes trust and reliability. Such a relationship may give the family confidence in their caring, and may also amplify the effect of the healthcare being given.

The sharing of experiences through conversation allows practitioners to get to know the people they have come to visit as well as to find out important information about the client’s situation. Families too will always have questions and this can provide a way to initiate and continue conversation together.
CONCLUSION

CBHC can complement the existing healthcare system, giving people more choices about the way they wish to live their life in the presence of disability or healthcare issues. Ideally, CBHC will also incorporate and develop community resources to better support healthcare for the members of that community. Families are the most important community resource that can be developed and strengthened with the assistance of CBHC. Towards this aspiration, CBHC practitioners must be cognizant of multiple potential expressions of “families” with the concomitant varying needs of members. CBHC practitioners need to keep the variety of family forms in mind when they visit clients so as to be able to collaborate with people who care and want to be involved in the life of a client. With the right relational support, those clients will then have the best chance of living their life in their own home and interacting with their local community. Indeed, for many of them, family is essential to this goal.

REFERENCE


Tania De Bortoli PhD
Speech Pathologist, Katoomba
The University of Newcastle, Australia

Diane Tasker PhD
Education, Practice and Employability Network, Australia

Catherine Murray OAM
Wentworth Falls, Australia
8. WHEN A NURSE COMES TO CALL

INTRODUCTION

Before we had formal healthcare structures, people looked after sick members of their families and their communities at home, often with visits from a doctor and a nurse. Indeed these sick people would then recover or die in those very same homes. People would either return to their usual duties, or be looked after at home as invalids, or leave that home in a funeral procession. Babies were also born at home. In today’s society, people also receive healthcare within their own homes but this seems to have become an addition to the more structured systems of hospitals and clinics. As healthcare expenses increase, it can be more economic to try to keep people out of hospital or to decrease the length of hospital stay. Sometimes, people may not be ill enough to go into hospital but may still need medical care from their general practitioners at home. In many of these cases it is up to the visiting community healthcare nurse to implement that healthcare. In addition, these nurses may have to advise and support the family carers too.

This chapter uses Australia as an example but much of what follows applies in many other countries. In community-based healthcare (CBHC) in Australia, different programs operate, including Hospital at Home, transitional care and integrated care between different services. The first two authors of this chapter are both registered nurses. Helen practises in both private and public health capacities; Hospital at Home and a private community-based nursing service. Jackie practised in a hospital setting for many years but now looks after one client with chronic and complex healthcare needs, with a private community-based nursing service. Jackie has also practised overseas. The themes within this chapter arose from conversations about issues and tensions in relational community-based healthcare nursing practice.

SETTING THE SCENE

For some people, home is not where you might expect it to be. It may be someone’s home but it can also be a nursing home, a group home, rental accommodation, a hostel, a “granny flat” at the back of a family home or even the street. In Australia, nursing homes have their own system of care and nursing but in all the other options mentioned, community-based nurses may assist clients with their healthcare needs. Community and Primary Healthcare Nursing includes ante- and post-natal care, Hospital at Home, aged care assessment, transitional care (from hospital to home), integrated care between different services, chronic and
complex healthcare and palliative care. Community-based nurses may work in public, private or not-for-profit organisations, in rural areas or in the city. Their care may be given to clients via a series of short visits but for some clients with very complex needs, for example, people living at home with the assistance of a ventilator to breathe and significant paralysis, they may need to work with their clients for 4-8 hour shifts regularly over long periods of time. CBHC nurses also translate and develop their nursing care knowledge into other spheres of healthcare, for example, mental healthcare, health promotion, care assessment, team management, case management and specialist nurse consultancy. The “Nurses where you need them 2016 eBook” (Australian College of Nursing, 2015) provides many examples and work stories of community-based and primary care nursing to better describe this broad array of nursing skill application in community settings. However for the purposes of this chapter, we are concentrating on the situation where a nurse comes to call on a client where they live, to provide a community-based nursing service.

Referrals for community nursing usually originate from general medical practitioners or from hospitals where a client may have had an admission and is returning home. Community nurses are often the first health professionals to become engaged with a client in the home setting but may then need to liaise with other services, depending on a client’s ongoing needs. Such other services could include the doctor involved with that client’s care, homecare (supplying assistance with home and personal care), community transport (for travelling to medical appointments and sometimes shopping outings), pathology, allied health services such as physiotherapy, occupational therapy, speech pathology, and psychology.

With so many other services often being involved, it may be seen that community-based nursing often provides a consultative and feedback role for many people. Community-based nursing in Australia has assumed such a role throughout its history and this role has continued, not least, because of the demand for community healthcare and the ever-increasing number of people requiring its services, often over wide geographical areas in Australia. Such consultation and feedback depends on clear, informed communication and the building of sustainable relationships between CBHC nurses, their clients, families and colleagues. The relationships between them are essential to both assessment and ongoing care for clients and we would argue, can provide community nurses themselves with motivation to continue practising this kind of work.

ISSUES OF TRUST

All nurses know that they are guests in their client’s home. The balance of power very definitely lies with the client. The nurse may think they know best and in many situations their healthcare knowledge may back up this perception but often they are usually only with their client for limited periods of time. All they can essentially rely on is the mutual wish between all concerned for any client’s wellbeing.
If clients and families trust a visiting nurse, they will be more likely to accept their advice. Even if there is little trust at first the advice may be remembered and grudgingly acted on. Trust builds respect. There are different types of respect that clients and their families can have for a visiting nurse:

- as a nurse – the fact that you are actually trained as a nurse and have specific knowledge that might be useful to clients and families
- as a human being, just like the clients and their families, and
- as a person.

All forms of respect need to be developed and built on with every visit. It will take time for clients and families to get to know their nurses and it will take more than one visit for the clients and families to find out what they want from, or need to know about, the nurses. Only then will they decide whether they can trust the nurses enough to confide sensitive information about their health, or their situation. In the following narrative, we can see the effect that such trust had in one particularly important situation.

I had been nursing this gentleman for a few weeks. He often couldn’t sleep and sometimes we would have a chat during the night. I think that because it was quiet and he knew we wouldn’t be overheard, he disclosed to me that one of his carers had become abusive towards him. He was very anxious about it and didn’t know how to stop it happening again. I think he had realised, not only that I would be able to take the action that was needed to protect him but, that he could trust me to follow through to ensure his safety. He couldn’t have confided in me if he hadn’t trusted me. I don’t take that trust for granted. It takes time and a certain sort of openness on my part to encourage the development of that trust.

Reflection

Like an onion, they have layers that you often discover when they are able to relax in the comfort of their own home. (Vanessa Crossley, RN in ACN, 2015, p. 34)

It must also be mentioned that a certain basic level of trust has to be reciprocal. For example, it is not uncommon for community nurses to be asked to visit clients with drug and alcohol healthcare problems, which can adversely affect a client’s behaviour and risk the visiting nurse’s safety. Feeling fearful when visiting a client can adversely affect the development of a helping relationship. That is beside the actual risk to the visiting nurse. A productive and successful interaction may still be possible, as long as there is support for the nurse, and there are clear parameters for safe care for all involved that are agreed upon and ensured. Indeed, continuity of community care can be crucial for the resolution of some of a client’s healthcare issues in such situations.
CLIENTS WANT CONTINUITY

When families care for their own family members at home, it can give the person being cared for a sense of security and continuity. There are shared experiences, shared humour and often no need to explain about issues to do with one’s medical condition or its history. One of the most constant complaints heard from clients with chronic and complex healthcare issues is their ongoing need to “tell their story” repeatedly to every new CBHC practitioner. This can be a particular issue for community-based nurses to deal with because of the nature of rostering of staff within community healthcare organisations. In another chapter, a client, Mark, explains his discomfort in having to deal with a procession of different nurses for the very personal issue of having an indwelling catheter regularly replaced. There is a sense of powerlessness in hearing of his experience with this situation.

To some extent, the regular presence of family members who are live-in carers, or regularly visiting carers, can assist with supporting clients in these situations. In such a case, the presence of family can be comforting. They can reassure and listen to clients for whom healthcare procedures can often be uncomfortable or painful. Sometimes, it will fall to family to advocate for the client with healthcare practitioners who cannot know them as well as the family can. There are different roles for family in their interactions with CBHC nurses.

Client and Carer as Facilitators of Interprofessional Communication

In a home where many different CBHC practitioners and care services are visiting, relationships and good communication can develop between the frequent and regular visitors, such as the nurses, and the client and family but not always so easily or freely with other visiting practitioners. This will be due to different times of visiting, heavy workloads and the spread of different organisations and private practices of the practitioners themselves. In such situations, it will become inevitable that interprofessional communication will rely on the written word and occasional phone calls. Some community nursing organisations will leave progress notes with the client but these will never tell the whole story. It falls to clients and families (and sometimes attending carers) to collate what they consider important to tell the next visiting practitioner. Practitioners too will ask the client and family members how a planned appointment had worked out, thereby reinforcing this communication role by the family and client and supporting the autonomy and confidence of clients and families in managing their own healthcare.

However, it should be recognised that, as with all oral narratives exchanged between people, individuals will choose what they talk about. From the point of view of the practitioner involved, there is a need to realise this and take it into consideration, knowing that what is told to them is what that person feels to be most meaningful. Supporting such dialogue with written communications between practitioners will hopefully broaden the detail and supplement the memory of clients. Written documentation can give visiting CBHC practitioners the context and information they need to proceed (and may also be a legal requirement).
Documentation will assist in the care of the client and complement the other less informal healthcare interactions occurring during home visits.

SO WHO AM I ACTUALLY COMING TO TREAT?

It is not uncommon for community-based nurses to have more than one client in the one home they are visiting because sometimes more than one family member has been referred for community care. It is not unusual in these settings for family members to ask the visiting nurse to provide an informal nursing service such as wound care, for example. CBHC organisations advise their nurses not to get involved in such situations, but rather organise or advise the person concerned to seek medical advice and referral first.

It can be argued, however, that by providing direct help to a client, the nurse will also be assisting the other family members indirectly. The emotional support provided to carers by nurses can be crucial. Without a healthy and positive carer at home the health and living situation for the client can break down. Carers often suffer from fatigue, depression, anxiety and fear as they take on the uncertain journey of home-based healthcare, some of which may end in the death of a loved one. There are health implications for carers from these physical and emotional pressures, such as decreased sleep, increased physical work of personal care and lack of respite. Nurses can assist carers to deal with these pressures.

The “Verandah Chat”

Many home-visiting practitioners will be familiar with the notion of “the verandah chat”. Usually, the carer will let the practitioner into the house. At the end of the visit, as a courtesy, the carer will see them out of the house as well. It is at this time that any underlying worries which the carer cannot voice in front of the client may come to the surface; how to manage a middle of the night emergency, who to ring if their loved one dies, “horror scenarios” they may have experienced with their family members that they want to tell the nurse privately. Sometimes these confidences are shared to simply relieve the tension of having the knowledge. Being listened to empathically can validate the experience and relieve the loneliness of being the sole carer in many instances. Sometimes, the carer may simply want information regarding a medication or a referral contact. In the following narrative, Helen remembers just such a situation:

“Nurse, I know the infection is really bad. Do you think he will lose his leg? Is there anything else we can do?” These are delicate issues and require much diplomacy. I can’t tell them what I really think. Often, it is not my place or judgement. So, I will say, “We are doing the best we can and you have great doctors who are keeping a close eye on this. We are coming to see him every day and if we have any concerns, we will ring the doctor. If you have any concerns between our visits, ring us right away”.
**Reflection**

Community nurses have to be diplomatic and be able to see the problem from the client’s perspective. Sometimes, they just have to be able to listen. Often, you cannot fix the problem but you can hear their story, be supportive, and be empathic.

**CONCLUSION**

CBHC nurses are, by the nature of their work and its context (requiring much travel), very busy people. However, we can see from the reflections by Helen and Jackie, how deeply they understand the importance of creating space within their clinical relationships to encourage clients and their carers to be able to communicate their fears and concerns. This interweaving of relationship with the more technical aspects of their practice is what truly makes them community-based nurses.

**REFERENCE**


Helen Fenech RN  
*New South Wales, Australia*

Jackie Finlayson RN  
*New South Wales, Australia*

Diane Tasker PhD  
*Education, Practice and Employability Network, Australia*
INTRODUCTION

For people with intellectual and/or physical impairment, healthcare is inextricably a part of the overall care they receive on a day-to-day basis. Paid carers do not always know the people they are caring for very well and need to make considerable efforts to develop humane client/healthcare worker relationships if they are to provide truly person-centred care. Creating opportunities for clients to participate in everyday life is necessary because clients may not be able to create these opportunities for themselves. The care that should be provided is based on the answers to more personal questions, “How would we like to live if we had such an impairment?” and “How do we want our loved ones with an impairment to be cared for?” An even greater question then occurs, “To what extent can we expect such care (and love) from personal contexts to be extended into the more formal contexts of institutional healthcare, such as group homes? In this chapter we argue that new possibilities to improve quality of life for clients with disabilities in institutional settings can arise through good relationships. The first author’s reflections on her experiences in a group home provide the basis for the ideas in this chapter.

SETTING THE SCENE

Australian society’s view of impairment and disability has changed significantly over the past 100 years. Within today’s society there is now an expectation that people with an intellectual or physical impairment will be cared for by society but also be enabled to participate in that society. Many young people with impairments live at home, supported full-time by their families. In some cases families cope with community support with paid carers coming into the home for a few hours each week. However for many, the only viable option becomes a group home or a nursing home. Group homes have become increasingly available during the past 20 years due to a gradual de-institutionalisation of large residential facilities in Australia. Such change in care environments has led to an improved quality of life and community integration for many individuals living with disability, however some community facilities have not adequately supported clients to experience a sufficient and satisfying level of social integration (Kozma, Mansell, & Beadle-Brown, 2009). Bigby, Knox, Beadle-Brown, Clement, and Mansell (2012) found

D. Tasker et al. (Eds.), Community-Based Healthcare: The Search for Mindful Dialogues, 87-92. © 2017 Sense Publishers. All rights reserved.
that routines in some group homes centred on staff needs rather than those of the clients who were not encouraged to take a more active role in their daily routines or within the community. Practice culture in such group homes was not client-centred and existed at the expense of client rights and quality of life. At the same time we recognise that there are group homes, which do provide quality client-centred practice and are actively supporting their clients to engage in meaningful activities and relationships. However, a particular question still needs to be asked. Do staff practices in group homes mean that they have become smaller versions of the old, larger institutions? One aspect of the old institutions was that staff decided how funds were spent and what care was provided.

Rather than taking a “one size fits all” approach, individuals and their families can now be supported to take a much more active role in deciding how their funding is spent and their care provided. Recent changes to promote such care in the area of disability have been introduced with the start of a National Disability Insurance Scheme (NDIS) in Australia. This scheme aims to foster inclusive and accessible communities, rights protection, economic security, personal and community support, learning skills as well as health and wellbeing (Commonwealth of Australia, 2011). Central to the NDIS strategy is the engagement of people with impairments and their families in the development, implementation and monitoring of the assistance they need, including the provision of paid support workers.

Without this essential workforce of paid support workers many clients in group homes would be unable to participate in the many aspects of daily life that the rest of us enjoy and take for granted. Their quality of life and wellbeing would be greatly decreased as a result. The quality of such paid care depends on support workers’ knowledge and skills. Most support worker learning occurs on the job because the knowledge needed is very client specific. The following vignettes (which are de-identified and composite in nature) explore the importance of relationships within these caring roles and illustrate some of the tensions that can arise from the point of view of a young support worker (the chapter’s first author).

THE JOURNEY INTO CARING

Support workers have to get to know the personality of the person they are caring for and their preferences and needs. The most important task for a new support worker is to establish a good relationship with the client. Many of the tasks required, (including manual handling, medication administration and wheelchair transportation) can be quite foreign to the support worker’s experience. It takes time for them to become comfortable with the everyday care needs of their clients and to then respond to these needs in a way that can engender opportunities for them to engage more fully with their activities of daily living. Such responsivity to the daily activities of a client can become “person-centred care” but only through the close human relationship that develops between support worker and client. Here are two vignettes to illustrate aspects of the developing relationship from a support worker’s perspective.
Getting Comfortable
You are often in very intimate moments with clients. I remember the first time I helped a client get dressed alone. I was acutely aware of how little I knew about her and was having trouble communicating because she was unable to talk clearly. I tried to start a conversation but felt so awkward and unsure of myself. She pointed to the other side of the room, to remind me that I needed to put on her ankle foot orthotics (AFOs) before I put on her shoes. Never having done this before, I struggled quite a bit. I never knew a foot could twist so many ways. Finally all that was left were the shoes; I quickly put them on feeling relieved that all the dressing was done. I looked up at the client and she had the biggest grin on her face. She burst out laughing and pointed at her feet. I looked down and realised I’d put her shoes on the wrong feet! As we both laughed together, all my awkwardness left.

Finding Opportunities to Know You
When I began, I found myself feeling like a child; everything was new and I needed to draw on information about my clients from other staff because my clients couldn’t speak. As I went along I found a multitude of photos of friends, family, past staff and past experiences. I think that building relationships and familiarity brings me, as a support worker, a sense of enjoyment and fulfilment and helps me to care for my clients better. These days I find myself telling stories with the clients about past things we’ve done together to new staff members. I am now adding to the memories they are building. Even though I am younger than other new support workers, I feel older through the experience I have gained in this particular setting. I can use my knowledge to help new staff get to know the clients. I no longer feel like that child who came here to work.

It is clear, from the second vignette in particular, that caring for someone in their own home or in a group home (or in fact any residential care facility) involves a large amount of trust, not least because support workers spend a lot of time alone with the people they care for and often make decisions on behalf of clients who may not be able to speak or act on their own. Good care relies not only on the way that support workers interact with clients but also how they interact and work with other involved workers. The adoption of a person-centred approach both towards and about clients and between colleagues in healthcare work situations needs to provide an atmosphere where people are taken care of emotionally as well as physically. An important aspect of this care is advocacy.

Advocacy can become a necessary part of the caring role for support workers, particularly when clients have significant cognitive and/or intellectual disability to contend with. Indeed, clients may not even know what their rights are or simply may not feel confident enough to advocate for themselves. It then becomes the
responsibility of all support workers to be alert to instances where clients are not being given choice or autonomy within their activities of daily living. This issue can be quite complicated when put into the context of a group home, where multiple support workers attend clients every day. It is easy for workers to fall into the ease and familiarity of routines rather than staying sensitive to how a client might wish their day to be organised.

_I remember asking one of my clients, Jonie, if she would prefer to shower earlier in the evening so she wouldn’t miss her favourite TV show. She replied that she wouldn’t, which surprised me as I knew how much she loved this particular TV show. When I probed further it turned out that one staff member liked showers to be done earlier. Jonie said, “I don’t want to get in trouble”. Unsure if this was the case or if Jonie had misunderstood, I mentioned to the staff member that Jonie wanted to shower later, but the staff member refused. In the end, to maintain the peace, I said I would shower her. Later I talked to the manager so the issue could be resolved._

Advocacy and person-centred care are interdependent but it is not easy to keep oneself alert and responsive in this regard or to advocate for a client’s rights. While this level of advocacy may seem to be a relatively simple matter, it is at the heart of caring and the relationships that develop within a caring relationship.

**RELATIONSHIPS MAKE THE MEANING**

People and their support workers can build their relationships by sharing time together. Accessing the community together allows both parties to relax and enjoy themselves but staff-to-client ratios and available funding can affect opportunities for clients to go out or spend relaxed time together with their support workers. Relaxation may not always occur when workers are busy carrying out personal care activities for clients, and support workers may also feel that they should not be enjoying themselves when they are working. The next two vignettes illustrate the importance of this aspect of relationship building.

**Sharing Time Together**

Taking clients out into the community was a whole new experience for me and I found outings to be highly enjoyable. Like everyone, clients really enjoy being out in the community doing things like shopping, going for coffee or tenpin bowling. Generally, people in the community are very kind and help out whenever possible. I remember being at a café with one of my clients, who had a most contagious smile. As our order came she conveyed her excitement very loudly, startling a little girl of about five years old at the table next to us. Her father explained to her that there was no need to be worried or frightened, that everyone is different and that she needn’t be scared of people with disability. I found his attitude heartening.
Another time I was out with another staff member and two clients at a café near a river. It was a beautiful day, and we were all enjoying the sunshine. Many people smiled or had a quick chat. As I went to pay, the waitress said someone had already covered the bill, leaving a note saying “thank you for brightening our afternoon”. I thought that you should never underestimate how kind people can be. My clients are quite restricted financially, so this gesture meant a lot.

*Opening Minds to Possibility*

One thing I find stimulating about accessing the community with clients is the problem solving needed. I remember one time taking one of my clients, Jenny, to the hairdressers for a haircut. The hairdresser, a woman (a few years older than me) was friendly, but a bit hesitant, as she had never cut the hair of someone in a wheelchair before. The situation was awkward at first as we tried to get the gown on Jenny and find the best spot in the salon for her wheelchair. However, gradually the hairdresser began to relax with us, especially after we worked out a way for me to support Jenny’s head to provide full access for hair cutting. We went back to this hairdresser many times after this first experience and I really enjoyed seeing the developing relationship between them, even though Jenny’s ability to speak was quite restricted. I could see how the experience of being in contact with someone with an impairment had really opened someone else’s mind to possibilities (just as it had for me). For many support workers it is the relationships and social interactions with the people they support that bring enjoyment and fulfilment. Such connections can be strengthened by sharing favourite pastimes, trying to understand the likes and dislikes of clients and exploring a mutual sense of humour through bantering and easy interaction. It is these shared moments, which may often have the greatest significance to both clients and support workers. Deliberately planning for such relational care is therefore necessary.

*Exploring Lifestyle Possibilities: Intentional Communities*

Families and support workers of people with significant impairment can often become the greatest advocates for lifestyle change. Their efforts provide a glimpse into the possibilities that can be achieved. The Benambra Intentional Community Co-operative in Canberra (“Benambra one year on,” n.d.) is one such example. Established by Sally Richards (a mother, disability services advocate and activist) and two other mothers, this project aims at providing young adults with physical and/or intellectual impairments the opportunity to live in an accepting, welcoming community. The young adults are also given the chance to contribute to their local community in mutually acceptable ways, despite their impairments. Unlike other care models, they have one support worker who lives with them, as a paid housemate and provides supportive care when needed. This community provides their sons with autonomy and an opportunity to contribute to their community. Without the advocacy and support of the parents and support workers, these clients would not have had the opportunity to live in their community. Opportunities can
be envisaged but then need to be made to happen for people who cannot do that for themselves.

CONCLUSION

People need relationships to be happy and healthy. The existence in modern society of group homes can be viewed as an improvement on the healthcare and living options that were available in times gone by even though there is still improvement to be made in this context. Good person-centred healthcare depends on the consistent development of relationships between clients and their support workers. It takes time to get to know someone. Such relationships need space and opportunity if clients and their support workers are to fully explore and develop the kind of care that all of us would like to experience if we were living with a disability. The stories of both support workers and recipients of care told in this chapter highlight the importance of the relational aspects of community-based healthcare, especially in the time-poor situations workers often find themselves. Time spent developing good relationships with clients is not time wasted.

REFERENCES


Gabrielle Klymenko
Occupational Therapist
Sydney, Australia
INTRODUCTION

Family doctors have existed in one way or another for hundreds of years. Indeed, physician training was established in Britain by royal charter from King Henry VIII in 1518 with The Royal College of Physicians of London. Australian medical practice devolved from this history. In today’s medical practice, a general practitioner (GP) is ideally someone who knows you and has known you for a long time. A GP can help identify your needs, knows about your relationships and has some understanding of how much you might need to be in control of your own destiny, including how much help you may need or want. Katriona, the primary author of this chapter has been in general medical practice for 40 years. This chapter was the outcome of a number of conversations held between the authors about the nature of Katriona’s work, expressed in commentary and derived clinical stories. The discussion within this chapter and its stories from practice (indented text) are formed from a combination of memories and current experiences.

SETTING THE SCENE

In general medical practice, clients can relate to someone they feel knows them, their family, their relationships and their beliefs; someone they have known over a long period of time. There are many types of medical practice in today’s society. Clients, especially young people, may just call into a random medical centre when they have a short-term medical concern or illness but also have a family doctor who they want to relate to on a longer-term basis for more serious issues of concern. With the rise of bigger medical centres, clients can usually get in to see a doctor quite quickly but may have difficulty accessing their own family doctor at short notice. If a problem is ongoing and their own doctor is needed or wanted by the client to deal with it more thoroughly and personably, that can happen too. There are advantages to be gained by clients in both situations. It is worth noting that seeing any doctor in a big medical practice allows easy access to a client’s medical records as they are usually owned by that centre. Some general practitioners may be able to visit the more frail of their clients even though the advent of community transport organisations has enabled people with disability and illness to more easily access their community and visit their local medical practitioner. Regardless of these differences, “relationship” will always be
important within the doctor client interaction. In this chapter we focus on practice where the GP has a long-term relationship with most of her clients.

CONNECTING WITH PEOPLE

It is more important to know what sort of person has a disease than what disease a person has.
(Hippocrates, 500 BC)

Role of the Family Doctor

General practitioners need to be well-trained clinically if they are to recognise, diagnose and medically manage pathological processes accurately and well. In identifying preventative health requirements, they also need to be well skilled in the knowledge of what preventative healthcare may be required and what regular testing and management is best for chronic illnesses. Decisions may need to be made about when to refer for specialist advice or when a problem is acute and requires hospitalisation. However, the human side of clinical interactions with clients is well recognised as being just as important. There are opportunities that arise from knowing someone well and having a relationship with them.

I often find when I’ve sent a client for a specialist opinion they return to see me, awaiting my response and interpretation of the specialist’s letter. They will not change their medication or act on any advice from the specialist until they have first discussed it with me. We have a relationship based on trust that goes back a long way and are therefore able to openly discuss implications of the specialist’s advice.

For example, I recently saw Norma, a very elderly woman with a cancer diagnosis who was sent for specialist opinion. She and her family returned with brochures about necessary chemotherapy and further appointments for yet other specialists; she had been “enlisted in the system”! Norma said that this was not what she wanted. She felt that her life had been good and she was ready to die. “I want to be pain free and comfortable.” I needed to discuss with the family giving her permission to say “No” to further active treatment and then to organise appropriate palliative care and support services. (Katriona)

Without a previously established trusting relationship and thorough medical knowledge of this particular pathological process, such difficult issues may not have been discussed so openly and honestly. Accurately and sensitively identifying what each client might want and need from the healthcare system is not an easy process. The doctor may need to follow through with multiple phone calls and conversations on their client’s behalf. Openness and trust are needed.
In present times, general practitioners tend not to do house calls unless a problem is extremely urgent or the client is immobilised and cannot come to see them in the clinic. People used not to have cars and there was very little public transport available either. Now most people can drive to the doctor’s surgery or get a neighbour, relative or community transport to bring them; it’s an acceptable “social” occasion. When they get there they are welcomed warmly by the office staff, some of whom may be 40 years younger than anyone else they ever see unless on TV! They see other people in the waiting room, perhaps having a chat with someone they have not seen for 3 or 4 years or they may get to interact with a young mother and her baby. They may even score a cup of tea from the nurse if sufficiently unwell!

I admit to feeling torn between the advantages to seeing a client in the office or in their own home. There are clinical advantages to seeing people in the office setting. All the necessary instruments for an appropriate examination and testing, as well as nursing assistance are available in the clinic if needed, unlike in people’s homes. Often in the past I’ve had extreme difficulty even looking down a throat in poor lighting or trying to examine an abdomen on a soggy saggy mattress on the floor. Dealing with all the animals on the couch has also been a huge impediment. However, sometimes it feels a critical part of the doctor client relationship is missing, and that an important issue affecting the client’s medical condition may be missed if not providing home visits.

After coming back from leave I have found that many of the people I look after in their own homes with chronic and complex healthcare issues have required hospital admission during my absence. I then ask myself; “What is the real reason for my visiting?” Is it that by regular visiting, I am picking up early signs or cues regarding a deteriorating condition and acting proactively? Is it that with my personal knowledge of that client and their confidence in me as their medical practitioner, they will confide more intimate problems than they would with other service providers? It is probably the combination of medical knowledge, relationship and the special permission given by decree of being a doctor to explore what might be considered personal and intimate matters. It’s acceptable, as a doctor, to ask to look in someone’s fridge, ask questions about toileting or sex or comment on a lesion you observe on someone’s leg, for example, “I’m concerned about that; can I have a look at it”? (Katriona)

Home visiting can have advantages because it becomes possible to see someone’s illness in the context of their living situation. A doctor can get a better feel for the totality of that situation and may need to step outside a medical role to help their clients with very necessary problems affecting their health and wellbeing.
Recently I went to see Muriel at home after her recent hospitalisation for acute heart failure. She was glad to be home and her daughter/carer offered me a cup of tea as we talked. When I asked to use the bathroom, I discovered that the downstairs toilet was broken and it was taking Muriel considerable effort to get upstairs to use the other toilet. Her use of diuretics further complicated this difficulty. My community contacts in this situation were used to find her a portable commode urgently. The family had not considered this as a need and Muriel hadn’t liked to speak of her difficulty. When I visited later that week, she was much relieved and very grateful. (Katriona)

Connecting with someone in their home space can open up possibilities for improved knowledge and understanding for the doctor to better assist that person with their healthcare needs in ways that are not otherwise obvious. Combined elements of relationship, knowledge and consent are indefinable but essential to providing good GP care.

CONTINUITY AND COORDINATION

Coordination and Chronic Care

In Australian medical practice, it is a major disadvantage to client care that general practice is federally funded whereas community and hospital care are state funded. This has led to duplication of services and poor communication between community health and general practice. GPs have no access to the internal community and health system computer databases and intranets. This means that they don’t get to see community health medical records or test results unless these are specifically directed to the GP by a hospital or community health worker. This does not necessarily happen because many hospital and community health staff may not fully comprehend the general context of a GP’s work and even the referral system can be very difficult to negotiate. Until these inconsistencies and incongruences are addressed, health costs will continue to be higher than they need to be, due to duplication, and the Australian public will continue to receive a compromised service.

People tend to expect their GP to be a coordinator of their healthcare. In more recent years (1999-2000) the Australian government introduced initiatives such as extended care plans (now called chronic disease management plans) for people with chronic and complex healthcare issues, subsidising access to allied health services and encouraging GPs to provide their clients with a care plan and regular review. There has also been an increase in the funding of services for people wanting to remain living in their own home, for example, the Home Care Packages Program. The advent of these initiatives has been useful but unless coordination of services is done efficiently, services which were initially designed to provide help can become fragmented and actually complicate clients’ lives.
Coordination and Serious Illness

The family doctor is someone a client comes to when they are troubled or confused with their interaction with the wider healthcare system. A general practitioner can assist a person to get their needs met in an open and honest way.

As a GP, a lot of my time is spent trying to coordinate care for my clients. Bernie was a lovely lady whose children I had delivered in my younger years as a GP, when I was still delivering babies most nights. I knew her well as both a client and an active member of our local community. I was quite distressed when a routine test led to a diagnosis of bowel cancer requiring resection and a colostomy bag. I had referred her to a local surgeon I’d previously had great confidence in. After she had seen the surgeon, she came to see me saying that she didn’t feel the relationship side of the consultation had gone well. She wanted a second opinion from someone her family had chosen. I comfortably wrote a referral, with her permission, making mention of the first opinion. Despite seeing the second surgeon, she subsequently had surgery with the first surgeon because it was closer to home and family, but now felt a lot more confident with the management plan as she was in control. She felt listened to by the second surgeon who had said to her that he was happy to operate on her but also happy for her to decide to return to the original surgeon. He was not concerned about owning her care but had been much better at explaining her condition and its implications. Her outcome was excellent, both surgically and emotionally. (Katriona)

In this situation, Bernie trusted me as her GP to understand her predicament and I supported her as my client to come to her own decision. Trust is necessarily a mutual process of understanding and acknowledgment. Bernie needed to have a very invasive surgical procedure. Her ability to cope so well emotionally developed in some part because she was listened to without personal judgement and encouraged to realise that she had some control over her own destiny. She may not have felt so comfortable if she hadn’t been supported in getting a second opinion.

“We’ve had our Ups and Downs”

Clients have varied responses to the interactions they have with their doctor over time.

Monica is now 80 years old but still quite independent. She regularly goes on overseas holidays. When I first saw her 25 years ago, she was extremely anxious and angry about a lot of things. We worked through many of her healthcare and relationship issues but on several occasions, when she arrived for her appointment, it seemed that her agenda for that visit was to tell me how angry she was – usually about me and something I had said to her on a previous visit. I found this very stressful and often also felt anxious myself when I saw her in the waiting room. However, whenever we finished an appointment, she always said that she wanted to come back and I didn’t
deny her. Last visit she said, “You’ve been my doctor for 25 years. We’ve had
our ups and downs but you know all about me. I am going to keep coming.
You’re my doc, doc.” (Katrina)

In this last narrative, Monica manages to sum up key aspects of a GP’s relationship with their client, the importance of acceptance, tensions, perseverance and the desire for longevity in GP/client relationships.

CONCLUSION

Within medical practices across our community, doctors and their clients have to carefully negotiate their relationships with each other. Such relationships are full of tensions and nuanced responses to those tensions. In this chapter, we have told some stories to illustrate a variety of relationship issues that might occur within general medical practice and how one GP has tried to assist her clients to work through such tensions. All the stories told in this chapter speak of the trust that needs to develop between client and doctor, building confidence of both parties and smoothing the way towards achieving satisfying health outcomes.

REFERENCES


Katrina Herborn MBBS, FRACGP, DipObs, MPM(Uni of NSW), FACPM
General Medical Practitioner
Katoomba, NSW, Australia
INTRODUCTION

Within western societies great gains have been made in terms of social inclusion and self-determination for people with physical and intellectual impairment. Only a short time ago people with impairment were often hidden away in the attics of private homes or locked away in institutions. More recently the responsibility for the social inclusion of impaired people as fully active citizens has been accepted and taken up by secular governments. As a result, in many countries there is public funding for specialised health services for impaired people. These services include community-based therapists who work within the lives of impaired individuals and their families, and within the dynamic relationships that impaired people have with their communities and the wider society. The work of these therapists both embraces, and is shaped by, the inherent complexity of normal living. In addition, community-based therapists are involved with a further set of relationships, those between the lives of the people they support, and the social structures that may constrain the ways these therapists are allowed to work. For community-based therapists, these complex relationships can create contradictions, tensions that are carried over to other relationships and must be negotiated through their work days/lives. There are nuances to these many relationships that need to be carefully
managed. We share some thoughts about these issues with you in the hope that they may facilitate your own reflective and mindful practice.

THE HOME VISIT: DARING TO GO WHERE OTHERS MIGHT FEAR TO TREAD

For most people their family home is a “sacred space” or haven where members of the family can relax, take refuge from the demands of the outside world, and be free from external judgements (Tasker, 2015). It is one place where family members expect a high degree of control over who comes into that space. The home is a place with its own particular culture, and the use of space, as well as the habits and dynamics of family members may vary noticeably from one home to another. Family rituals, such as meals and bathing routines, may be important to family members’ sense of security and comfort. These occasions may also be intensely private. Outsiders are not usually observers or participants. Yet these are the very situations in which community-based therapists find themselves assessing the needs of clients and implementing interventions designed to improve a client’s quality of life. Community-based therapists may experience varying degrees of acceptance into the homes and lives of the people they support. They may witness/experience the nuances of family dynamics, which can challenge their own attitudes to life and even their personal and professional values. The authors of this chapter recalled experiences of trying to participate respectfully in such situations, whilst trying to work supportively with families whose lives were not unfolding as they might have wanted. As individuals, the authors could not avoid being affected in some way by their involvement in these complex interactions. Therapeutic interactions are necessarily reciprocal in nature (Ek, 1990). The following stories are fictitious accounts but reflect an amalgamation of real experiences.

A State of Shock

Harry was a small boy who had profound intellectual and multiple impairments. Maggie, his mother had had a busy career in the corporate world and, like many career women, had come to parenthood in her forties. The child who emerged in the first few years of her son’s life was not what she had expected and proved to be the end of her familiar life. By the time the authors came into Maggie’s and Harry’s lives, Maggie’s husband/Harry’s father had left. Maggie found herself a single parent of a small child whose needs were so pervasive and confusing – her life became about hospitals, medical appointments, equipment, and an entourage of professionals. Usually when the authors arrived at the home, Maggie was not dressed, and had dishevelled, unwashed hair. As she looked around at the piles of unwashed dishes in the sink, the piles of laundry in various stages of being washed, and other paraphernalia strewn amongst the wheelchair, lap tray, wedges and other therapeutic equipment, she said: “I used to be really organised and productive. Now, most days I feel like I’m in a state of shock”.

100
Reflection

Working with Harry in his home brought up many issues and tensions for the therapists who visited him. They were aware that they were first and foremost fellow human beings, and secondly therapists. They struggled with how to be present for Maggie’s suffering with the circumstances of life for both her and Harry: how to be compassionate, empathic and non-judgemental. The therapists were challenged to regard the whole family as their “client” and to be flexible around what Maggie most needed. Harry’s therapists had to carefully consider how to implement interventions that might make a difference within the family’s circumstances. Regardless of how much choice Maggie felt she had in allowing the therapists to witness her life, they would always LEAVE at the end of the sessions. As the therapists got into their car to leave, they often had a plethora of feelings; guilt about walking away and leaving Maggie with her life; a disturbing humility about what they were being allowed to witness; persistent doubts about whether they could make enough of a difference to Maggie’s and Harry’s lives, and relief that this was not the life they were living.

Driving away

As for me,
I wash my hands.
I smile,
I lift my face to the sun as I leave.
I open the car and sink into the hot interior,
letting the heat soak into my body, cover me like a coat.
I drink some water, check my diary for where I must be next.
I turn on the cool air.
I drive away.
(Tasker, 2015, p. 273)

The challenge for therapists who visit clients in the community is to be able to continue to turn up in the midst of the chaos that can arise when a life is disrupted by illness, accident or disability. Therapists need to take time to develop their relationships with clients so that they can continue to be responsive to their needs. Relationship building is not a tidy process and does not always easily flourish within the “packages” of organised healthcare provision. In today’s healthcare world, therapists can often find themselves trying to be accountable for the minutiae of their practice, always needing or feeling the need to account for what they do with their time. This may have been exacerbated by the increase in middle management within disability organisations, who have to be accountable to their funding bodies. We pose the questions: “Why do professional therapists with years of training need to be managed to this degree? Do we not want these therapists to exercise the professional judgement that they have developed over the course of
DE BORTOLI ET AL.

their practice, especially when that care properly reflects the needs and goals of their clients?”

**TAKING A VILLAGE VIEW: THE VALUE OF MORE INFORMAL NETWORKS**

It takes a village to raise a child. (African proverb)

In encountering the “full catastrophe” (Zorba the Greek) of other people’s lives, therapists can discover that some of the most efficient and effective ways to meet their clients’ complex needs are informal, fluid, organic, and often not pre-programmed. Sometimes the “bits” of involvement by a therapist that have made the most difference to the quality of a person’s life have not been planned, discrete “sessions” in a therapy room or even the person’s home. Instead they have been spontaneous and sometimes chance encounters, the result of networks that may be informal. For example, a therapist may know that someone has a piece of equipment sitting unused in the garage, which might be useful to someone else and so they drop in and pick it up. It may travel in the boot of the car for a week or so before the therapist chances to be passing by that other person’s home and can drop it in. Such incidents remind us powerfully that people with impairments and their families are part of communities, and that therapists are also part of these communities. For example, other supports may evolve organically from an activity that has been tried by one family, and then “word gets out”. All the community-based therapist need do here is facilitate the “linking up” of these families, and perhaps drop in to the activity if requested by the families. In the following narrative, such “linking up” can be seen within a community context well known to many of us, a local kids’ soccer game.

**Linking up for Community Activities**

John was a community-based occupational therapist whose son played soccer for the local soccer club. John arrived at soccer one Saturday morning to find another parent, Janet and her child Jeff who happened to be receiving therapy support from him at the time. It was clear that Jeff wanted to be included in the soccer game but had never played before. He was also having some difficulty coping with a physical impairment, which caused him to be quite unbalanced when he tried to kick the ball. At first John felt some conflict about his dual roles in this situation but very soon he found himself using his professional knowledge to collaborate with the coach to gently modify the team dynamics and the coaching. He mentioned to Janet that there may be other children with physical impairment who might wish to join in as well. Together they began planning to develop a soccer team that could accommodate children experiencing different degrees of physical impairment, and the issues this could cause for them in a sporting context. John found that his role as a professionally trained therapist became melded into his roles as a parent and a community member. Indeed, the combination of these identities proved powerful for facilitating the inclusion of children with physical
impairment in a community sporting activity. As therapists with long practice histories, the authors argue that it is not always necessary to strictly separate the different areas of our lives. Rather, such blending of roles and identities can enhance possibilities for people with impairment living within the same communities as their therapists.

**Reflection**

By being involved in the local soccer club, John found that he could:

- put parents in contact with each other so that they could share ideas and resources and provide mutual support
- facilitate inclusion of children with physical impairments in a fun, local activity with other neighbourhood children
- facilitate social interaction for children with physical impairments
- enable children to regularly practice and develop gross motor, fine motor and co-ordination skills
- support children to follow instructions and learn the rules of a game
- support children’s and parents’ feelings of well-being and social membership.

Informal networks of communication can, however, be more difficult to develop for therapists working within formal organisations. It may, as a result, be more difficult for therapists to provide support that makes meaningful differences to peoples’ lives. Individual therapists are faced with a challenge of managing potential impacts of regulations about their practices on the flow of interactions and support that occurs within “community”?

The example of the “village model” (described above) contrasts with the “over-organisation” that can at times be experienced working within Government-driven structures and processes. Yet, there are inherent tensions and risks for community-based therapists however they work. Therapists must find ways to practise that will make the most meaningful differences to peoples’ lives while balancing this with the structures and systems within which they work, in particular funding arrangements and the practicalities of billable hours. In addition, therapists are conscious of always behaving ethically towards the people they support and others in the community, and upholding the practice standards promoted by their specific discipline. Even more fundamentally, the authors of this chapter reflected on what being a therapist means, and “the hook” of doing work just because it needs to be done. For therapists, there is a personal cost of caring, and a risk of depletion. Individual therapists can be subsumed by the needs of organisational structures and systems for standardisation and centralisation. For community-based therapists, the tension increasingly emerges as to how to continue to do caring work; the reason that they became therapists. Therapists can find themselves increasingly faced with advocating and doing informal, voluntary work to fill the gaps that they see emerging and widening within society. However, whenever therapists do such work for free, it further devalues the work of supporting the participation, self-determination and social inclusion of people with disability.
CONCLUSION

The question remains: How do we as professionals and fellow citizens help those amongst us facing overwhelming challenges associated with physical and intellectual impairments? Perhaps we can do this by always holding before us ideals of person-centred care and always asking ourselves further questions: How can the well-being of our clients and their families best be integrated within our professional responsibilities as therapists? How can we help them flourish within society? Tensions for therapists between caring and the exigencies of professional practice are perennial. In the end, there are no definitive answers, only an ongoing, mindful dialogue involving the people we work with and the people we work for, about how we might all participate in the evolution of a more caring society, where balance can be gained between care for others and care of ourselves.

ACKNOWLEDGEMENTS

The authors would like to acknowledge the people they have supported, their families and others in their community, who have inspired the reflections captured in this chapter.

REFERENCES


Tania De Bortoli PhD
Speech Pathologist
Post-doctoral Research Academic
The University of Newcastle, Australia

Bronwyn Couch MSpecEd
Occupational Therapist
Hazelbrook, Australia

Diane Tasker PhD
Education, Practice and Employability Network, Australia
12. THE CARE ASSESSOR’S STORY

In the Field, from the Field

INTRODUCTION

Within modern community-based healthcare in Australia, care assessors are employed by community-based healthcare organisations to facilitate the assessment and integration of healthcare services into the context of the home of people needing such care. That integration process brings with it challenges and complexities that we need to be aware of and that need to be managed from the outset if community-based healthcare is to be successful for all concerned. In this chapter, we introduce issues of interest that can cause tension from the perspective of a care assessor (first author, Sharyn) who works within communities in New South Wales, Australia. In the interests of privacy, the vignettes used here have been constructed to demonstrate practice issues experienced by both authors over the past 40 years. They do not tell the full story of any particular person, alive or dead.

SETTING THE SCENE

A care assessor is a person who is formally recognised as being able to judge the holistic care needs for people with chronic and complex healthcare requirements. The care assessor role has arisen because of local needs on the ground but also more generally in response to the World Health Organization’s (WHO) initiatives to promote primary healthcare for people with disability and complex healthcare issues within their own homes and communities. These local and global initiatives attempt to have the following characteristics:

– Empowering people to take control of their healthcare and making essential healthcare available to everyone (WHO, 2005)
– Advocating and monitoring processes to ensure that health is promoted by and with people, not on or to people (WHO, 1997)
– Focusing the provision of healthcare to the contexts where people live, work and play (WHO, 2002).

In NSW these initiatives have been put into action in the form of healthcare “packages” that can be provided to people in their own homes. Following the provision of funding for someone’s care, care assessors undertake an initial assessment and plan care according to approved funding and in collaboration with
clients and their families (as the primary decision makers). For positions as care assessors, practitioners need to hold current registration through the Australian Practitioner Registration Agency (APRA) as a Registered Nurse.

A care assessor’s role can vary from minimal to complex involvement depending on the healthcare issue/s to be addressed and possibly the type and amount of funding involved. People receiving community-based rehabilitation or support for activities of daily living may have constantly changing needs. They may also expand their range of choices if they regain more autonomy within their own home and community.

**COMPLEXITY OF CARE NEEDS**

The complexity of healthcare for someone living at home raises important questions about social and family needs. For example, someone with a brain injury who requires mechanical ventilation, catheterisation and enteral feeds is going to need different support depending on personal circumstances. Are they living in a spacious house with a supportive family or a tiny house with difficult space problems? Are there support workers with language problems, noisy and abusive family or neighbours, or a multitude of pets? If so, which is the most complex or difficult issue to be addressed? Is it the challenge of the physical space, complex clinical needs, psychosocial issues, the personalities of the clients and the support workers or the dynamics between all these? Clinical needs are often not the most challenging issues. The most complex issues can be the relationships between the client needing healthcare, their family or support network, and the people visiting to help (the care workers, therapists, nurses, doctors). All these issues need to be managed if we are to provide integrated care.

**Integrated Care**

Consideration must be given to include the organisation of assistance with activities of daily living (ADLs). Such services can include assistance with shopping, visits to the doctor, assistance with domestic tasks, socialisation or assisting people with showering and dressing. All these areas can impact a client’s health and wellbeing and have become an important component of the integrated nature of community-based healthcare. Support workers can provide assistance with carrying out health-related activities for the client concerned or assist them to carry out a living activity they wish to perform. For example:

Mary lived at home but was mostly wheelchair bound although she was able to stand by holding onto a fixed support or with the assistance of someone standing beside her to steady her. She had always closed her curtains in the lounge room at night but with increasing physical problems, it had become too difficult to do. Following advice from a community-based physiotherapist, a visiting care worker was able to stand beside Mary and using a handled belt around her waist, support her to close the curtain independently. This simple activity gave Mary great satisfaction. The care worker then assisted her to make a meal for dinner.
When community-based healthcare practitioners come to assist people in their homes, they can be presented with a wide variety and spectrum of human experiences and behaviour. While this makes for an interesting work life with many stories to be heard, and sometimes wondered at, with opportunities to listen and to learn, many situations can be dysfunctional and present not just difficulties but also dangers for visiting staff. It is a delicate process to balance the need of a client to be autonomous in their decisions with a responsible “duty of care” towards them. This balance is generally known as “dignity of risk”, a term that includes a person’s right to decide their own actions, even in the face of risk and is based on the complex issue of whether a person is able to make such decisions. It is the job of the care assessor to assess and manage such a melange of complex human and healthcare situations and ensure clear lines of communication are kept open.

COMPLEXITY OF COMMUNICATION NEEDS

Our society is generally aging and improving acute care has resulted in increasing numbers of people surviving severe accident and illness but with chronic care needs. We therefore have an increasing population of people who can expect to have community-based healthcare. General medical practitioners and motivated families may strive to ensure that vulnerable people access and maintain their contacts with community-based health carers. This may not always be sufficient to prevent people “falling through the cracks”. Clear lines of communication are essential, at all levels, both interpersonal and inter-service. Jack’s story below gives an example of the importance of communication in the face of such complexity.

Wishes and Needs

The complexity of communication for people seeking community-based healthcare starts with a referral from an agency such as an insurance funder, an Aged Care Assessment Team (ACAT) or from an individual (self-referral). Care assessors can be presented with the varied and sometimes conflicting needs of the client and their families. Care is also limited in terms of the finance provided and families sometimes struggle to accept those limitations especially when a significant part of the day is not “taken care of” by the care provider. A good example of a situation needing careful management of complex communication can occur with diagnoses of dementia. Dementia is becoming increasingly prevalent and families increasingly want, and expect, their elderly relative with dementia who wants to stay at home, not to be relocated into a facility setting, but rather continue living at home, even with a deteriorating mental capacity.

Jack had a diagnosis of dementia and chronic respiratory and cardiac disease and after referral from the local ACAT team, received a community-based care package involving approximately 5 hours of care each week. At the initial care assessment, conducted in his home with a care assessor and his daughter, Josie,
Jack insisted that he was quite alright, “I’m OK. I don’t need anything.” His daughter reminded him that he often became so short of breath that he couldn’t get home from shopping. Jack was quite independent at this stage and able to get on a bus and go shopping although he sometimes forgot what he went shopping for. His medical conditions often necessitated regular hospital admissions (4-6 times each year) and he needed to take a variety of prescribed medication regularly. He also needed extra medication following any hospital admissions.

Community nurses visited intermittently and had completed a management plan for Jack’s health condition to help with this varied pattern of poor health that influenced his pattern of living. Support workers followed the advice given in the community nurses’ healthcare management plan to ensure that adequate healthcare was provided as Jack needed it. Jack’s care assessor had to facilitate a wide network of contacts and communication needs. Particular areas of difficulty included:

- A shy attendant care worker with poor English
- Jack’s nearest family member, his daughter, who was very concerned for her father, lived 5 hours away and worked long hours
- Jack’s hospital medical consultant for his cardiac issues, was concerned that Jack was presenting for admission to hospital too often
- Jack was often reporting incorrect information (Jack keeps telling everyone that he is quite independent and does all his shopping and housework himself, which is not true)
- Concerned healthcare staff trying to safeguard Jack’s privacy and person-centred care with full dignity and choice being maintained.

Managing healthcare needs for people can be challenging at the best of times, compounded by clients challenging their need for care, such as in situations where cognitive ability is impaired. Communication has to be both detailed and comprehensive if the wishes and needs of clients are to be adequately and sensitively met. At the same time it is important that care does not go beyond professional boundaries.

CARE AND COLLEGIALITY

Care workers need to be kind, caring, intuitive and effective communicators and able to follow instructions. Care workers need to ask themselves the question, “Am I am friend or helper?” which can be a challenge. In the following narrative, the very human tendency to do more than has been agreed upon (from the service organisation point of view) is explored, including a difficult situation that arose where a support worker crossed professional boundaries regarding responsibility and care.
The Blurry Lines of Care

Maurice lived on his own following the death of his wife and had a supportive network of family who lived close by. He managed quite well with the provision of a package of care and family support. Family, although close by, were full time workers and had small children to support. Care workers visited the home a number of times a week to assist him with various care needs and domestic tasks. Tasks were identified, agreed and clearly defined in Care Plans for workers to perform.

Maurice, being the social gentleman he was, found it quite easy to form a bond with the workers. One of the care workers over time immersed herself in his life to the point of inviting him to her home for barbecues, taking him to local community functions and cooking meals in her home for him. The family expressed concern to Maurice’s care assessor about this situation. The daughter explained that she had spent several hours cooking meals for Maurice, only to find that the care worker had done the same, quite outside the designated tasks planned by the care assessor and agreed by the co-ordinator and family.

Such blurring of boundaries can create confusion for clients and feelings of inadequacy and intrusion for their families. The support worker concerned may also not understand why her caring efforts have not been better received. It is worth asking the question, is it a good idea to regularly change workers to reduce the risk of dependence on any one worker and how does this sit with the client’s need for continuity? Care workers who spend long periods with clients in their home may find a challenge in maintaining the distance of professional relationships with clients they feel personally close to. Even experienced community-based healthcare practitioners know that they need to be constantly alert to provide person-centred care while maintaining a professional demeanour. The integration of healthcare and support care in community-based healthcare situations sometimes involves a blurring of those boundaries which can often be difficult to see.

CONCLUSION

At present, the area of community-based healthcare is expanding, possibly faster than society is prepared for, particularly in regards to consumer-directed care. There are many aspects of such care that need to be carefully thought through for future planning and staff education. Contact and feedback with all stakeholders in community settings needs to be sought and taken into account if the expectations of the community and the people needing healthcare in the community are to be met. Care assessors are well placed to negotiate such difficult territory and assist clients to receive the care and services they wish for as well as providing value and accountability for the funder, the provider organisation and the support worker.
REFERENCES


Sharyn Williams RN  
*Senior Care Assessor*  
*Southern Cross Community Healthcare, NSW, Australia*

Diane Tasker PhD  
*Education, Practice and Employability Network, Australia*
INTRODUCTION

Acute neurological incidents, for example, stroke, traumatic brain injury, infection or cardiac arrest are sudden, often unforeseen and always life-changing. When people have been hospitalised for such events, the time eventually comes when they leave hospital and start to live the rest of their life in a community setting. The first author in this chapter is a consultant rehabilitation physician who has been working for more than 20 years with people who have experienced such events and are living in the community. The co-author is a physiotherapist who has also worked within community settings. Their clinical paths have occasionally crossed over the years but, when they decided to write this chapter together, opportunities arose to discuss how interpersonal relationships in professional clinical practice affected, and were affected by, the reality and complexity of community-based rehabilitation for people who had experienced brain injury. The following narratives concentrate on the reality of life experienced by these people and the elements of relational healthcare considered to be important for them to be able to live well in the community again.

SETTING THE SCENE

There has been a growing awareness of the long-term difficulties that many people with traumatic brain injury (TBI) have in regaining a meaningful life. A significant number of individuals continue to have trouble in their daily lives after they leave the rehabilitation setting (Tait, 2003). This has led some TBI programs to alter their focus towards working in the community, rather than within the rehabilitation centre.

Community-based rehabilitation programs for people with TBI differ from the traditional centre-based models in several ways. Firstly, the emphasis has shifted from ameliorating impairments and disabilities towards re-establishing everyday activities and thereby increasing participation in normal life. The process of assessment involves identifying roles and skills important for a person with TBI within community contexts, as assessed from the perspective of that individual, close others, employers and educators.

Psychological support is required to assist the person with TBI and close others in coming to terms with lasting personality and lifestyle changes and...
forming a new post-injury identity. Ideally, follow-up contact is maintained over an extended period to provide support in dealing with new problems as they arise with changing circumstances. Where the person with TBI is not immediately able to return home from hospital, this therapeutic input may be provided within a residential “Transitional Living Program”. These programs provide therapy to enhance independent living skills and interpersonal skills, and eventually support the move to independent living, with continuing attendant care or other supports as necessary.

A more common model of service provision is that of a “community-based team”. This generally comprises occupational therapy, speech pathology, clinical and/or neuropsychology, physical therapy, social work services, vocational counselling and educational assessment as needed. Generic services in the local community may be utilised. Assessment, goal setting and interventions are carried out within the relevant settings in the community. Interventions may involve repeated practice to establish routines, development of compensatory strategies, or modification of a task or environment to maximise successful task performance. Extra assistance may be employed.

TBI has a significant impact on caregivers, and on the family as a whole. Family members provide most of the ongoing support of a practical, social and emotional nature to the person involved, and family interactions are an important determinant of the injured person’s psychosocial adjustment. Families need to be involved in the rehabilitation process, and to have access themselves to supportive counselling and assistance in finding and dealing with service agencies and managing financial and legal issues. The adjustment process for families is likely to be lengthy. Multi-family group interventions may provide opportunities to share experiences and enhance family functioning and social integration for caregivers. Access to family therapy services can assist families who have difficulty in grieving, or in adjusting to the new roles and expectations that the injured individual will have within the family. All forms of family support need to be available over the lifespan of the person with TBI. In particular, provision of support in managing behavioural issues following TBI is of paramount importance. Family caregivers report this to be the greatest source of stress when caring for their injured relatives.

MAKING A SAVED LIFE WORTH LIVING

What you see in the news does not show the years of effort ahead for the person who has had a brain injury, their family and the changed life that eventuates. Rehabilitation is “what happens next” after a person suffers a disabling injury or illness. It does not save lives, but can make the saved life worth living.
Rehabilitation services are the “missing link” between hospital and community-based services. Rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides people with the tools they need to attain and maintain independence and self-determination. The following narratives explore some situations that highlight relational issues for the people concerned.

Managing Expectations

Community-based rehabilitation teams do not cure people but they do help people to improve their function despite their impairment, and to resume, as far as possible, their former roles in society. Most of us, if we had suffered a serious injury, would aim to resume our previous abilities but in the face of a permanent physical or cognitive impairment, we would need to “come to terms” with that reality and build a style of living to accommodate it, keeping some dreams and hopes alive. Kath reflects on the process of helping to manage expectations for Ruby, a client who had sustained a serious brain injury.

Ruby was a young woman who had sustained many fractures and a traumatic brain injury in a car accident. For many months, hospital staff had considered the very real possibility that she may need to live in a residential facility with high levels of personal support. However, Ruby and her family were determined that she would come home to her husband and children. Many months of rehabilitation later and with consistent therapy support, she achieved this goal and was finally able to consider the possibility of working again. She had been left with a hemiplegia and some difficulties with planning and short-term memory but these difficulties continued to improve slowly over time.

Prior to her injury, she had been a teacher. She could still teach in the classroom, although getting back to work took over a year as she tried repeatedly to convince her school that she could actually do it. However, her employers still said she couldn’t come back to work permanently because she could not supervise sport or manage playground duty. She did tutoring at home and some part-time work but could not return to her original school. Eventually she worked at another school doing much less than she had been doing before. I think she could have gone back to doing her classroom job but she would never have been able to run and chase the kids playing sport. Often, the person may need to change goals when their original goal proves not to be realistic. However, it is still important to assist them to aim for their goals as far as possible, finding other ways to express that goal if at first they do not succeed.
By far the major part of living a life after brain injury happens after the injured person leaves hospital. Often health professionals train mainly in acute care situations and learn to make decisions based on the most usual functional outcomes to be expected after different sorts of injury. However, for the person who has had the injury and their family, that cannot be the end of the story. The message from Ruby’s story is that persistence with flexibility can achieve a worthwhile life.

Persistence and Encouragement

Life after a severe brain injury cannot be as it was before but persistence and willingness to try with the encouragement of therapists, doctors, and most of all family, is essential if clients are to sustain hope that they can build different but satisfying and meaningful lives in the future.

One weekend, John and Mary were driving in their local township when they were struck by another car on Mary’s side of the car, causing her a severe brain injury. It took many long months of intensive rehabilitation and much heartache and adjustment on both her and her family’s part before she was able to go home in a wheelchair but she was still unable to stand without assistance and had problems with many different aspects of life. John assumed full-time care for Mary and their house and gradually they worked out new ways to do what had previously been ordinary activities of their daily living. Together with the community-based rehabilitation team they worked towards small goals for Mary, some of which she was able to achieve and others not. In particular, she had really wanted to be able to walk with a stick in the house and go to the toilet independently but they had not been able to make this activity fully independent. Along with her other losses, Mary also struggled with grief at not being able to be the mother she had been. John continued to feel guilty about the accident and what he might have been able to do to avoid it. Their life had been irrevocably changed.

Both of them worked hard to overcome Mary’s physical and cognitive difficulties, constantly supporting and encouraging each other along the way. There would always be increased difficulties for them both and decreased mobility for Mary but, over some years, they developed a new lifestyle, which accommodated her impairment and allowed them to regain some life enjoyment.

Dignity of Risk

People with TBI and their close others need to be actively involved in community-based rehabilitation, which should occur as far as possible, within the context in which a given role is normally performed. Education of the injured person’s network of contacts, including family, friends, employers or teachers is very important because the use and adaptation of
strategies needs to continue throughout the person’s lifetime, far beyond the availability of professional therapeutic input.

For many clients, the physical and cognitive challenges of living with TBI will strongly impact their desire to resume activities that they had enjoyed before their injury. Cognitive problems may include increased fatigue, memory difficulties, lack of insight, difficulties managing planning and impulsive behaviour. Physical problems may include visual deficits, motor weakness and balance problems. All these issues can lead to a lack of safety in what may have previously been normal activities for them.

Brian, a young man in his twenties sustained a severe TBI but wanted to regain the social life he had enjoyed before that injury. In particular, a football weekend with his mates was coming up and he wanted to attend with them. To assist with this goal, his community-based rehabilitation team met with his friends and worked through how to manage the risks, such as balance difficulties, fatigue and increased impulsivity in the context of alcohol use so that he could join in without feeling different.

Clients, families and healthcare practitioners need to work through such challenges so that clients can try to develop the life they want.

CONCLUSION

Community-based rehabilitation has been shown to be effective but it is not always available for everyone when they need it. Because of the method of funding through different government bodies, it does not happen naturally or easily. When community-based rehabilitation is available, the outcomes for clients and their families are enhanced and their quality of life can be improved. Processes for community-based rehabilitation are complex and different for every person with TBI, requiring input from all members of the team, particularly the client and their family. Teams can often accomplish more than individuals working alone.

The narratives above explore concepts of the relational aspects of such rehabilitation needed during transition back to community-based life after brain injury. While community-based rehabilitation has been described as the “glue” between acute hospital care and the development of a new way of living for someone with TBI, its success relies on the relationships built between clients, families and healthcare practitioners, particularly when community-based.
REFERENCES


Kathleen McCarthy FAFRM (RACP)
Consultant Rehabilitation Physician
Sydney, Australia

Diane Tasker PhD
Education, Practice and Employability Network, Australia
INTRODUCTION

Our state of mind is the bedrock of our whole life - affecting personal relationships and family roles, interactions in our community, the work or occupations we pursue, and the fundamental ways we view ourselves and our abilities and aspirations. The whole of society loses out when we squander human potential, when we limit the capacity of people to be our friends, colleagues or leaders because we do not offer them the right assistance when they need it. (Mental Health Commission of NSW, 2014a, p. 3)

We know that one in five people will experience a problem with living (Buchanan-Barker & Baker, 2006), mental disorder or condition in any year, and about one in two people will experience such a problem in their lifetime (Mental Health Commission of NSW, 2014a, p 12). Given this high prevalence we could suggest that problems with living fall within the range of lived experience of human beings. Of people with these experiences, the majority will experience a high prevalence disorder such as anxiety or depression. Far fewer people will experience a low prevalence disorder which includes psychosis, bipolar disorder and major depression. Regardless of the severity of the problem, most people will need to access community-based mental health support for themselves or for their family at some time during their life.

In Australia, publicly funded community mental health services are part of a network of services incorporating community managed support services (non-government organisations or NGOs), peer workers, public mental health services, housing, vocational and recreational supports. Author, Maria is a mental health nurse with experience of working with people with lived experience of mental health issues and their families in both community and inpatient mental healthcare settings. These people may have first experienced a challenge to their mental health and emotional wellbeing during childhood, adolescence or at any subsequent stage of their development. Their first contact with the mental health support sector may be via their general practitioner, self-referred to a community-based mental health assessment team, or following presentation to the emergency department of any general hospital. As well as working as a clinician, in the past decades Maria has worked in service development, practice development and education within the public mental health system in New South Wales.
FITZGERALD

SETTING THE SCENE

The move from the institution to community-based mental health services evolved during the nineteenth century, influenced by the advent of psychiatric medication - Cade’s discovery of lithium carbonate as a treatment for bipolar affective disorder in 1948, adoption of chlorpromazine in 1952 for the treatment of schizophrenia, tricyclic antidepressants in the late 1950s, and haloperidol for the treatment of psychosis in 1967. In 1978 Australia was a signatory to the World Health Organization’s Alma Ata, signalling a shift from hospital to primary healthcare that was community based (WHO, 1978). This resulted in a gradual appearance of community mental health services aiming to enable health, thereby increasing local availability of accessible and effective supports that were acceptable to the people using them to maintain their health, or to support them in their recovery. The development of community mental health services followed, both in the community health setting and the local hospital in parallel with the closure of tertiary psychiatric institutions. Fifty-four percent of the NSW mental health budget is now spent on inpatient care. Queensland and South Australia had the largest increase in community mental health service funding per capita of the Australian states and territories in the four years to 2011 with 7.9% and 5.8% respectively (Mental Health Commission of NSW, 2014a).

PLACING THE LOCUS OF CARE WITHIN THE COMMUNITY SETTING

LIFE IS NOT A PROBLEM TO BE SOLVED.
LIFE IS SOMETHING TO BE LIVED,
AS INTELLIGENTLY, AS COMPETENTLY,
as well as we can,
DAY IN AND DAY OUT.
LIFE IS SOMETHING WE MUST ENDURE.
THERE IS NO SOLUTION FOR IT.

(Szasz, personal communication, as quoted in Miller, 1983, p. 290)

Mental health rehabilitation in the past was concerned with re-establishing a person’s sovereignty, that is, being able to refer to their own locus of control in making decisions about their lives and their relationships. When a person has a disruptive problem with living, mental health nurses work with them so that they can gradually resume such agency. The following story demonstrates how a community mental health nurse works towards minimising the disruptive effects of a mental health treatment by maintaining and strengthening the client’s agency and relationships in their own home and community.

JULIA’S STORY

Julia is nineteen years old and lives with her mother, Joan, her stepfather Jim and two sisters, Jane who is sixteen and Jill, four. Her mother contacted the
MENTAL HEALTHCARE IN OUR COMMUNITY

community mental health service, concerned that Julia has not been attending her university preparation course at TAFE (Technical and Further Education) and has been isolating herself in her room. When her mother tries to engage with Julia about what is happening for her, she simply smiles, tells her how beautiful she is and then sometimes begins to cry. She seems unable to engage further. Joan states she is wondering if Julia is really talking to her friends on her mobile phone, or whether perhaps she is carrying out conversations with imaginary people; she is not sure. Joan requests a visit to see if the mental health clinicians can get Julia to talk to them about what is going on for her.

The community mental health team visited each day and after a time Julia’s story came together. Study had always been hard for her and she had found high school increasingly difficult. She found her mind wandering when she needed to concentrate and sometimes time could pass without her realising it. She thought she may have been day dreaming a lot.

The clinicians asked her about her childhood and Julia described being close to her sister and her mother but frightened of her father, a veteran who had served overseas. He lived nearby and had post-traumatic stress disorder. When she was small he suffered severe depression and he was very critical of his children, also unpredictable and irritable. Julia felt she had always been easily distractible. She had dropped out of school midway through year twelve when her anxiety became too much and had started hearing voices. Julia explained she felt better when she smoked marijuana and gradually the voices had subsided. She wanted to go to university, so commenced studying towards her higher school certificate (HSC) at TAFE, only to find the anxiety and the voices returned. The mental health clinicians visited Julia and listened to her family as well. They spoke to her doctor and arranged for her to see a psychiatrist who prescribed some medication to help her sleep. Julia learnt about the unhelpful effects of marijuana on her mental health and with support ceased using it. The mental health clinicians made arrangements for her to see a trauma counsellor. Julia’s mother and stepfather were introduced to the carer services that provided both information and support. Julia’s sisters were also included in family discussions and Julia felt safe to talk to them too.

It took another three years for Julia to get to university. While continuing to work with her counsellor she returned to TAFE and gained the support of student services, completing her Higher School Certificate over two years. While studying, Julia commenced part-time work with a youth mental health service working as a peer mental healthcare worker. In this way she used her lived experience of negotiating her own mental health issues to encourage other young people who were similarly experiencing problems with living. Julia graduated from her tertiary studies and ceased her peer support work when she gained employment as an early childhood teacher.
Julia’s story is an example of the way healthcare can be provided with access to community mental health services which are part of a network of care and in a specific situation where it is possible to keep a young person safe in their own environment. Were Julia unable to be safe at home, requiring admission to a mental health unit during her time of crisis, the outcome may have been very different. Julia had several years with problems with living but she did not have those years away from her family and social networks. Her experience became enriched by the relational work that she did and the reciprocal value of peer support work. While some degree of stigma may be attached to accessing mental health services, this may be compounded when a person is admitted to an inpatient psychiatric unit. Here control over many aspects of their life may be taken away, and the loss of agency may be compounded by isolation from their family and friends. People may also witness traumatic events in inpatient psychiatric units.

RESPECTING THE LOCUS OF CONTROL IN THE PERSON

I must not fear. Fear is the mind killer. Fear is the little-death that brings total obliteration. I will face my fear. I will permit it to run over me and through me. And when it has gone past I will turn the inner eye to see its path. Where the fear has gone there will be nothing. Only I will remain. (Herbert, 1990, p. 302)

PAUL’S STORY

Paul was thirty-six years old and living on his own in a public housing flat. For twenty years he was relatively disengaged with his local community. He felt a bit unmotivated because he was unable to get work. He had been in and out of hospital, sometimes for long stretches of up to twelve months at a time.

Paul returned home following a two-month admission to an acute mental health unit. Taking a major tranquiliser, he found himself sleeping a lot and putting on weight. His mental health nurse worked with Paul to find out how he wanted to spend his time. After much consideration about his fears, he decided he would like to start a computer skills course at TAFE, and identified the steps he would need to take to get there. First he needed to get used to getting up each morning, showering and making breakfast. He also decided that he needed some help learning to live within his means.

They discussed the unwanted effects of the medication that Paul was taking, including the risks of metabolic syndrome, obesity, high blood pressure, cardiovascular disease and diabetes. Paul decided the first step was to seek a medication review and an appointment with a dietitian, and to think about starting to exercise regularly. He had heard about the peer workforce but until this time did not really know what they did. He made a call in case he could access peer support services to help him with his plan to get ready to go to TAFE.
Paul met his peer support worker the following month. The nature of his work was explained as a type of coaching. This contrasted with rehabilitation Paul had in the past in that the work he did with his peer worker was self-directed.

COMMUNITY-BASED MENTAL HEALTHCARE FOR THE FUTURE

Language is how we express the ideas in our minds, and is therefore a most powerful agent that can reinforce separation, stigma and discrimination or, instead, work to overcome our differences and emphasise the things we have in common. (Mental Health Commission of NSW, 2014a, p. 5)

The issue of language and the changing meanings of terms and the ways people describe themselves and their experience is fundamental to the provision of mental healthcare. Labels that objectify the people we serve diminish our relationships with them and undermine the self-efficacy we are striving for together. The future of mental healthcare will most likely incorporate less of these binary, oppositional linguistic principles. In the future, we need to welcome the person with lived experience of problems with living and their family and peer support workers as full partners in care.

Working with Aboriginal and Torres Strait Islander people, we can learn from the collective approach embedded in deep listening and traditional healing circles that value integrating family and kin into the collective story (Dudgeon, Milroy, & Walker, 2014); (Mental Health Commission of NSW, 2014b, p. 22). Similarly, a Finnish model of mental healthcare called Open Dialogue, which involves a dialogical and networking approach (Seikula et al., 2006; Borchers, Seikkula, & Arnkil, 2014), could have much to offer.

To make such change occur, there needs to be a range of skilled care providers available, who can offer any variety of therapies that a person may need. There is also a need to offer opportunity for a person and their network to engage in deep listening, to sit with the social, emotional, relational and psychological distress that may manifest as part of their problem with living. Increasing engagement of peer support workers in the provision of mental healthcare demonstrates a society which values the experience gained through their recovery journey. Traditional disciplines offering care may be challenged by this approach but with increasing use, peer support workers could be welcomed into mental healthcare.

CONCLUSION

Our society is looking for ways we can all live well and ways we can offer the right assistance at the time we need it so we get the most favourable result. To achieve this, we need to come up with new ways to increase opportunities for people to gain mental health literacy. Such efforts may include social and emotional strength acquisition in the schoolroom, gaining resilience, sensory and emotional integration skills from early childhood and throughout life. To prevent the social isolation experienced by people using the mental healthcare trajectory of the past, it
is important that community-based supports to negotiate problems with living are part of a larger care network, integrated within a tiered approach which responds to the recovery needs of the individual and their family or carer in the community where they live.

REFERENCES


Maria Fitzgerald CMHN, RN, MN(Hons), MN(Mental Health)
Katoomba, Australia
DEBBIE HORSFALL AND JOY HIGGS

15. PALLIATIVE CARE

Living and Dying at Home

A CARER’S MEMORIES

My mother died
in the morning of yesterday’s yesterday.
I was her primary carer for nine years at home.
We said goodbye so many times –
sometimes ... just in case ...
on the way to the hospital or before surgery;
sometimes, wordlessly
with her changing hold on life –
each phase captured in her eyes
in my treasured photographs.

I remember a special day –
a bittersweet moment
two weeks before her final goodbye –
she was pain-free
and so blessedly clear-headed.
“Thank you my Darling
for all your love and care.”
And, of course
I said this back to her.

My life was so much richer
for getting to know her
again and again –
in each new life she embodied
as her life and challenges progressed relentlessly
but with special times of joy and belonging –
dancing together, walking in the park, visiting friends,
and just being together.
Every day with her –
no matter what ...
was a blessing!
LIVING AND DYING AT HOME

What does it mean to live at home at the end of life? What does it mean to support someone through this? In this chapter we present a dialogue and narratives from life and research experience about this challenging and amazing part of community-based care.

It is clear that most people want to die at home (PCA, 2010), not in intensive care, or a hospital ward or even a hospice. And the people they want around them are people they know, people they trust, and people they can laugh and cry with.

NARRATIVE 1

Last week I was in Grafton where the jacarandas and silky oaks are in full bloom; where the cabbies are talking of swarms of flying foxes and where it has not rained for 8 weeks. The burnt off grass was crunchy underfoot as I walked to meet Gary, who was waiting for me on the porch. A self-employed builder he built the house 30 years ago. He and Helen had raised four children there. He was about my age. So was Helen when she died from bowel cancer exactly nine months ago.

We go into the coolness of the kitchen. Gary gives me a glass of iced water. There are plates of fruit and biscuits on the surface. Mugs wait to be filled with coffee or tea. “Shall we do it here or out back?” he asks. I look at the kitchen table, and then ask to look out back. The view is stunning. Golden fields of swaying grasses with the Grafton hills framing the horizon. “Helen loved to sit in here” he says. “Let’s do it here then” I say.

We carry in chairs from the kitchen; arrange them in a circle around the two-seater cane couch. I place the recorder on the table, put consent forms and information sheets on the chairs. Gary hesitantly spreads the photos he has taken around the recorder. A cup of tea; a chair; a toilet; pantry shelves brimming with food; a list of names; a mobile phone; a basket full of prescription drugs and syringes. They are photos of what was important as he cared for his wife.

The others start to arrive. Six women. One of Helen and Gary’s daughters, two work mates, one family friend from school, a hockey buddy, a sister. This is the core group, the group who made it possible for Helen to die at home, in her own bed. These are the people who did the ironing; took Helen out; lay on the bed with her; washed up; delivered meals; showed Gary how to use the washing machine or just gave him some time to himself. These are the people who laughed and cried and came around for happy hour drinks at the end of each day.
They have come to tell their stories, and to support Gary to tell his. They talk about love and sadness. About how they just knew what to do when. Or how they stumbled along, showing up, being there, not really knowing what to do or say but coming anyway. Taking the risk. Knowing it was necessary and that Gary couldn’t do it on his own. Knowing that it takes a community, however small, to do the work that needs to be done.

Half way through, Pam, who is silently crying, says, “I know this is not what we are here to talk about, but Gary there’s something I need to say. This is the first time I’ve been back in the house since Helen died. I am sorry I haven’t come before. I just couldn’t. I’m such a sook.” Susan pats Pam’s thigh. Marilyn hands her a tissue. Gary makes a joke. We pause. The others ask the things they have not wanted, or dared to, until now. Does he still sleep in the bed? What days are the hardest? Would he do it again? There are tears and shrieks of laughter muddled together. Emily goes to make cups of tea. Marilyn makes a speech about how proud she is of him. I notice how they are still taking care of each other.

“You know the first blow is when you get the terminal diagnosis,” says Gary, “the kick in the guts is when you are then told it has to be done in hospital. Helen hated hospitals. We all do. The food is horrible. The bed is uncomfortable and only has room for one. There is no privacy. There are visiting hours. The toilet can be occupied when you need it – and she had bowel cancer. The toilet was important. Having her at home just made it easier for all of us.”

I leave overwhelmed at just what ordinary everyday people are capable of: their generosity, their willingness to show up and support each other when times are about as tough as they can get. And I notice how this changes them, their relationships, and their communities. And I am humbled by their willingness to talk to a stranger in the hope of doing more good in the world. As I walk back across the crunchy brown grass to my waiting taxi I am reminded of the words of the head of a palliative care unit when I asked him how they support home deaths: “Really what we can do is, we can provide reassurance around the fact that it is natural. Yes, there’s some stuff that’s going to happen that may be confronting but none of it is rocket science really ... we can ... take them through the steps of what is technically a very simple thing often, but emotionally very heavy and complicated”. You know, when people in Australia are asked where they would like to die, 80% say at home. Yet only about 17% of people die where they chose, with most dying in institutions. This was one story of a small group of people who worked, played, laughed and cried together so that Helen could die where she chose. This was a story of ordinary people doing something quite extraordinary.

Helen and Gary’s story illustrates that it is possible for a person to die at home and do this well. It also illustrates that for this to happen it is essential that they have a strong – albeit sometimes small – network of people caring for them and each other; people who show up, who share the emotional and physical work of caring
for someone who is nearing death due to illness, or old age. What is also essential is that the primary carer, in this case Gary, is also cared for and supported. Both the dying person and the primary carer/s need to be held in a strong web of relationships woven by people they trust. What is surprising, perhaps, is that when people speak about caring for someone dying at home, the people they speak about, the relationships which they most value are those of friends, family, neighbours, and work colleagues. Why this is surprising is that healthcare providers, while essential, are not as important in a day-to-day sense as the people who form what we call the informal care network. What is important about this is that if we are to shift to home-based palliative care where people get the care they need in the place they want it, then we need to shift away from a healthcare-centric view, one which places healthcare providers in the centre of what is taking place. This is not to say that their skills and knowledge are not important and necessary. They are.

CARING AT THE END OF LIFE

Helen and Gary’s story was written after conducting a focus group as part of the Caring at End of Life Research Project. Taking a sociological, rather than a biomedical stance, we wanted to provide in-depth understandings of how informal and formal caring networks work together when someone who is dying is being cared for at home. Informal networks are friends, family and neighbours while formal networks are services, health professionals and volunteers. We wanted to know if, and how, these networks and relationships are mobilised, strengthened, built or transformed as the daily lives of people involved in caring for a dying person are profoundly altered; and what affect these networks and relations have on care-giving. And we wanted to document what these networks do, what tasks of caring they undertook.

We asked carers, caring networks, volunteers and service providers to tell us their stories of home-based end of life caring. Overall we spoke with 88 healthcare providers and 308 carers and members of caring networks from across NSW and ACT via interviews or focus groups. The research was strengths based: that is, instead of asking why more people were not dying in their place of choice, we asked: how are ordinary people supporting each other to care for someone dying at home; what happens when they do; and, how can we capture their narratives, making them public and illuminate the space of the possible (hooks, 1994). This seemed an important positon to take.

CHANGING OUR POINT OF VIEW BY HEARING ALTERNATIVE NARRATIVES

The sociological literature moves beyond a biomedical model of the caregiver based on alleviating the assumed long-term burden of caring, to a portrayal of the embodied and lived experience of caring. (Sadler & McKevitt, 2013, p. 50)
Most of the literature about care-giving at end of life focuses on the burden of care narrative (see for example: Grande et al., 2009; Zapart, Kenny, Hall, Servic, & Wiley, 2007; Australian Bureau of Statistics, 2012) and it is this burden that healthcare provision is oriented to alleviating. This burden narrative, we suggest, could be a barrier to more people dying at home. By that we mean that the narrative can affect both people at the end of their lives and healthcare provision/providers. If the dominant narrative is that when we need to be cared for we become a burden to the people caring for us, then we may resist this. We may decide that we will not burden the people we love. We may then decide that, for their sake, we will do our dying in an institution. This narrative also influences healthcare providers who see carers as people who are burdened and who need to be relieved of this burden. Consider the following examples of alternate narratives.

**NARRATIVE 2**

_We had a great grandfather (who died) before our grandmother died and I was emotional about that and it was kind of the same but when I came into this it was a little bit easier._

_And I’ve been emotional but it wasn’t hard and it didn’t feel scary or anything. It had to happen._

_You can’t hide it from someone because otherwise they’re not going to know. They’re not going to know at all who is there before them._

_It wasn’t scary._

_I think everyone around me made it a lot easier._

[Focus group member aged 13]

**NARRATIVE 3**

_My mum passed away 6 weeks ago and I nursed her at home with cancer._

_Helen did me a big favour because she showed me you can get through it._

_A month ago a girl came in. Her father was dying of cancer, and she was nursing him at home._

_I pulled her aside and said “look I did it a month ago, it’s the hardest thing you’ll have to do but you’ll always be happy.”_ [Community pharmacist, interview]
NARRATIVE 4

I talked to everybody.
I tell everyone because
I just had no idea
that that’s what went on at home.
I’d never seen it before.
I mean
everyone I’ve lost –
I’ve lost them in hospital
so I’d never seen
anything like this before
and I tell everyone.
Just amazes me.
[Carer, interview]

NARRATIVE 5

I’d come from the hospital setting.
Working here made me better
at working with families.
It helped me learn how good the process can be.
How manageable it can be.
The experience here
allowed me to do a better job
working with those daughters who
looked after their father at home.
[Palliative care nurse, focus group member]

An alternative narrative is to see caring for a person who is dying at home as normal and natural (as indeed it used to be). In this narrative, the healthcare we provide becomes person and community centric. It is all a question of what point of view we begin from, whose narratives we privilege.

LEARNING TO BE PART OF AN ALTERNATIVE NARRATIVE

Nobody taught me what to do
and how to cope.
My life had not prepared me for this.
I had to learn about the system –
to negotiate the care I needed to get for her.8
Always – I didn’t know what I didn’t know.
Battles, searching for obscure information,
making sense of frustrating and often contradictory
rules, procedures and information.
In many ways this system talk became the backdrop.
In the foreground were other ways of understanding and being.
Much of it realised through experience.
The way I learned to be nurse, doctor as well as daughter at home, late at night.
Should I call the ambulance?
Or will this be just another long wait to answer the same old questions then more traumatic tests and terrifying separations with distant strangers.
I learned to make choices for her I learned, painfully, to survive if these choices were mistakes.
This was a soul-saving piece of advice from a human-skilled specialist: "learn to forgive yourself if you can’t always cope serenely and if you make mistakes”.
Another player on our foreground stage was a palliative care nurse who visited our home.
She gave my mother permission to go ... and she helped me find the words to say “you can go now Mum – go to Dad and give him a hug from all of us.”
I’m sure, I’m sure I saw her smile as she slipped away.
Learning to be a carer for someone who is dying – can be much more complicated than loving and caring for them. Being part of a caring network for someone at the end of their life must be one of the toughest situations to manage but people manage it and report that it is often transformational: people learn new skills and knowledge; death and dying is often demystified and seen as a part of living; people take these new attitudes, skills and knowledge into other relationships and work in the community developing individual and community death literacy, social capital and the community’s capacity to care for each other. And they learnt that they could do it! So, caring does not need to be a burden nor does it need to be an isolating experience for either the carer or the person being cared for. Rather, caring can contribute to social capital with carers and the cared for being part of a vibrant and growing network of relationships. When this happens caring for someone at home models both the practice of caring and develops compassionate communities (Horsfall et al., 2012).

Of course caring for a dying person, particularly at home, is extremely demanding work – physically, emotionally, psychologically and spiritually – and people can rarely do it well without complex networks of community and service-based support. Undoubtedly, it takes a community: friends, family, neighbours, schools, church groups, work colleagues, all play an essential role. They can bring food, help with chores such as washing, gardening, shopping, dropping children at school, making cups of tea for visitors, providing firewood.

Some people in this research sat with the dying person to give the carer a break. We heard about bedside “happy hours” or helping to continue family rituals and celebrations. Others took a more hands-off approach by sending text messages and dropping food off at the doorstep. Others provided emotional and/or spiritual support. All of these things and more were needed and provided. What was most important was that people provided what was actually needed by the carer and the dying person – not what they assumed, or thought was needed. People in the networks spoke about feeling privileged to be able to care at such an important time in someone’s life. They spoke of love and joy and laughter as well as nervousness and a desire to “do it right”. In fact people from the informal caring networks often treasured this time with many going on to support other carers caring for someone dying at home. We also found that in many caring networks there was at least one person who had previously been part of an informal caring network. So, it does not seem to put them off, in fact quite the opposite.

CONCLUSION

Refocusing palliative care to a more social approach emphasising relationships and community can, we hope, help mobilise and maintain care networks. If this hope is realised then ultimately more people will be able to die at home, and carers will be well supported by informal and formal caring networks. An important aspect of support is the provision of reliable information from healthcare systems and links to alternative narratives. In this digital communication age people (particularly,
tired, stressed and overworked carers) shouldn’t have to hunt all this information out for themselves.

Healthcare providers need to be able to see, and accept, that what is important to people at the end of their lives is to be comfortable (the aim of palliative care) but also to be comfortable surrounded by their intimate objects, their friends, pets, gardens, and families. The difficulty here is that these things are not spoken about: we don’t speak about where we want to die; we don’t speak about the joy and love and laughter associated with supporting each other; we don’t speak about death and dying much at all. Yet it’s going to happen to all of us. And it’s only going to happen how and where we want it if we start having these conversations with each other and start sharing stories of possibility.

It’s important that healthcare providers are able to have these conversations with people, to ask what is important to them; what it is that they want to achieve; what help they need and in what way. And rather than assume that dying at home is impossible for most, to embrace the possibility that this is not so, providing that people have information and support networks. The role of healthcare providers then becomes one of making sure that support and networks are sustainable and that people who provide unpaid caring are not exploited or isolated. Informal carers, and networks, need supporting.

Carers may need permission and practical hands-on help to gather networks together and to negotiate the type of help they need and this we suggest could be the beginning place for conversations between healthcare providers, carers and people at end of life. Our hope is that conversations, not needs assessments, about death and dying will become common place so that dying is demystified and de-institutionalised and that dying well, in places and with people and things of our choosing, becomes an accepted part of living our dying well.
NOTES

i Personal communication.

ii Names of people and places have been changed to protect their privacy.

iii The narratives/data in this chapter (unless otherwise noted) are taken from the Caring at End of Life Research Project 2011-2015, funded by the Australian Research Council and conducted in partnership between the Cancer Council of NSW and the University of Western Sydney. (Horsfall and colleagues)

iv Horsfall and colleagues who conducted the Caring at End of Life Research Project 2011-2015.

v These data poems are taken from the Caring at End of Life Research Project transcripts. All the words are the words of the participant. However, they have been slightly rearranged in order to tell the story.

vi Personal communication.

REFERENCES


Debbie Horsfall PhD
School of Social Sciences and Psychology
Western Sydney University, Australia

Joy Higgs AM PFHEA PhD
Education, Practice and Employability Network, Australia
INTRODUCTION

Twenty years ago case managers were relatively rare creatures; but now many community-based healthcare agencies have a member of their team who has some level of case management or care coordination as their primary role. Everyone wants to live a good life and has the right to try and live their life the way they want. Sometimes chronic healthcare issues, disability, psychosocial challenges and complex and changing services can interfere with such goals. Human rights and legislated changes to healthcare and disability support systems have shifted the driver of services from the provider to the client. This is the space where case managers now work. This chapter explores insights arising from the author, Jane’s practice as both an occupational therapist and recently as a case manager in a specialist healthcare service for children and adolescents. In the following narrative, Jane reflects on the rise of the role of the case manager.

SETTING THE SCENE

Disability services have experienced a significant cultural shift from clinician-directed to client-directed or person-centred care, where the emphasis is upon people with disability having a say about the services and supports that they want and need. This cultural shift started with the introduction of the Declaration of Rights of Disabled Persons (United Nations, 1975), which recognised the rights of people with disability. In Australia, this was followed by the NSW Government inquiry into health services for the psychiatrically ill and intellectually disabled known as The Richmond Report (Richmond, 1983). This report recommended that dedicated mental hospitals be largely closed down and that people be supported in the community. As a result, funding began to be re-directed into community-based support. In 1996 the Australian Government introduced the Disability Services Act (DSA). Amongst the principles of the DSA was the right of people with a disability to access services, which support a reasonable quality of life, to participate in decisions that affect their lives and to receive services that pose the least restriction on their rights and opportunities. The DSA and its partner document – The Disability Service Standards, guide the shift to client driven care in Australia. While many people are quite capable of managing their own healthcare or disability needs and supports, some people may need or want the assistance of a
MEIKLEJOHN

case manager to negotiate systems of care, especially during times of transition or changes in health status.

According to the Case Management Society of Australia and New Zealand (CMSA) case management is a process of eight steps: identification of need, assessment, including client risk, planning, care co-ordination, monitoring, transitioning and review (Marfleet, Trueman & Barber, 2015). It can be particularly needed in situations when a client:

- has been newly diagnosed and needs to learn how to negotiate their impairment and consequent disability
- enters a new service system
- has psycho-social issues such as intellectual or learning impairments, drug and alcohol issues or psychiatric difficulties with living.

There are many variations of case management depending on whether it is hospital or community-based, the client’s disability and the approach taken by the case manager. In community-based case management, the services are usually mobile rather than office-based (Lukersmith, Millington, & Salvador-Carulla, 2016). This allows the case manager to develop a better understanding of the needs of the person with disability, their family and their circumstances.

COMPLEX CLIENTS OR COMPLEX SERVICE SYSTEMS?

In Australia, people with disability are now legislated to receive support within their local communities. As a result many more agencies are involved in providing support to people with disability. An unfortunate outcome of this shift is that the system has grown and become quite fragmented, making it challenging for some people to navigate. I often hear the phrase “complex family situation” and this is often the reason given for a request for case management. What does a complex family situation look like? It may mean the family is from a culturally and linguistically diverse background or simply that they have a tenuous housing situation. Often, the main reason that clients and their families require case management is due to the complexity of the system. As a case manager I organised a case conference for one such “complex” family.

Troy had recently been diagnosed with a neurological motor condition and autism, requiring ongoing involvement with specialist health services. He saw a number of therapists through hospital clinics but was also entitled to Federal funding for private therapy under the Helping Children with Autism (HCWA) program.

The family had many things to learn in order to manage Troy’s disabilities, but they were capable and clear about what they wanted, if somewhat unsure about what support might be available to them. Although Troy’s therapy needs were extensive and required multiple disciplines to be involved, from an individual therapy point of view, his needs were not particularly complex. However, the case management process for Troy and his family involved significant time spent on planning support and identifying which service would do what tasks. Because of
the number of therapists and services involved, much of my time as Troy’s case manager was spent on collaboration and ensuring communication was clear and understood by everyone involved.

At Troy’s case conference, twenty people sat around the table and that was with several apologies. In the end he still had three occupational therapists involved in his care because no one funding body or service provider covered all his needs. The complexity lay in the multitude of services involved, often due to different funding arrangements, none of which could provide for all of Troy’s needs. In such a situation, it is no wonder that case management was needed. Even for people who are very capable of managing their lives, the very nature of our complex healthcare systems is difficult. This does not make the families “complex” but rather the systems they have to negotiate.

**BUILDING CLIENT CAPACITY**

While case management job titles differ and their scope of work varies, the one thing they have in common is a primary role in helping clients navigate a service system (or systems) to identify and advocate for the supports that they want and need. As a case manager, I have observed that there are times when clients and their families cope with a service system and other times when they require assistance. The need for active case management can be intermittent in nature as some families learn to navigate the systems. James and Rachel were one such family.

James lived with his Mum, Rachel, and his younger brother Ben. James had intellectual and physical impairments and attended the local high school’s support unit. Rachel had her own mental health problems that significantly limited her capacity to access her local community, but she was well aware of these and she managed this impact quite well on her own.

Ben had some challenging behaviours at home and the family struggled to cope with these. Rachel was a single mum and was slowly navigating her way through the many services that both her children required. The National Disability Insurance Scheme (NDIS), a new way of providing support to people with disabilities in Australia, was being rolled out in the area where they lived and James was eligible to receive support under this scheme. Participants of NDIS are required to develop a plan, which outlines their goals and the supports they need in order to achieve them. Most people without disability would rarely think about their life in this way. Rachel requested some assistance from me, as a case manager, to help her learn about this new way of receiving support.

New service systems such as the NDIS do require a new skill set for clients and their families, in order to understand how to define and access the support they require. This family did not want or need much case management, just a little help to learn the ropes of a new system. When Rachel and James next need to meet with the NDIA to review their plan, I suspect that they will be able to do this on their own.
NOT EVERYONE WILL HAVE THE SAME CAPACITY

These days, people with healthcare or disability related needs are expected to seek supports from many services. For clients who have a new diagnosis, and particularly those with a learning difficulty, intellectual disability, or mental health issues, the expectation to seek and direct service providers can be overwhelming.

Our answer to this problem is often to have a case manager involved to advocate, collaborate and network with, and for, the client. There are some clients who we know who are likely to require case management support for longer periods of time and indeed, may not get to the point of being able to manage their, or their family members’ healthcare needs without case management support at regular points along the way.

Ruth is a grandmother who was appointed guardian of her 3-year-old granddaughter, Annie, who had autism and a developmental delay. Taking on the full-time care of a toddler with disabilities was a huge undertaking. Annie was very active throughout the day and woke 4 to 5 times a night. It did not take long for Ruth’s health to deteriorate. I met Ruth and Annie at an early intervention group. Ruth came with a list of challenges related to her care of Annie. She wanted the best for her, but was so tired that just getting through the day often seemed an almost impossible task. Ruth had to accept that caring for her grandchild was going to be a different journey than caring for her own children. My first task was to get some practical support to help Ruth in the mornings and the evenings, times which she had identified as being stress points for her. After a lengthy referral process and a trial with some support agencies, Ruth realised that she didn’t really want other people coming into her home to help with caring. The priority then became helping her to improve Annie’s sleep routines. Ruth’s situation was very challenging, but not so uncommon. Not only was she taking on the care of her grandchild, which is a difficult task for a grandparent; she was also taking on care of a person with disability. Both were new roles and both required new learning for Ruth.

My role with Ruth was to be a regular contact throughout the period of confirming Annie’s diagnoses. I helped Ruth to identify the main issues that she required immediate help with and what type of supports might be most useful (assessment and planning). Sometimes I made referrals for Ruth and spoke with the agencies on her behalf to check that they were able to provide the service (facilitation). On one occasion Ruth had taken Annie to the local Emergency Department (ED) because she was concerned that Annie was having a seizure. A doctor at the ED had first questioned why Ruth had care of Annie and then insinuated that her concerns were all in her mind. Ruth came to me very upset about how she had been treated. I encouraged her to make a formal complaint to the hospital (advocacy) and to discuss her experience and her concerns with her paediatrician.

The supports provided for Annie included helping Ruth organise preschool and an early intervention service. She had a paediatrician and saw several other medical specialists but found many of these medical appointments challenging. She often had difficulty understanding what was going on in her interactions with medical
personnel. Ruth and I talked after each appointment to go through what had been discussed and recommended. Ruth had to learn about many conditions and treatments and how these could impact on Annie and on her own life.

Ruth and Annie, unlike Rachel and James, are likely to continue to require case management support, particularly during times of transition for Annie, such as starting kindergarten or high school, or a deterioration in Ruth’s health. Ruth has the added complicating factor of becoming an aging carer for Annie and this will in time, present another set of issues that Ruth may need support to manage.

Reflection
Having disability or chronic healthcare issues requires significant new learning for people. They must seek out and learn about health conditions, treatments and interventions, agencies and services that they have probably never heard of. They often have frequent and ongoing appointments and people coming into their lives and their homes on a regular basis. The diagnostic phase of disability or healthcare issues can be a frightening and exhausting time. Previously held hopes, dreams and aspirations are challenged. People grieve the lives that they had imagined for themselves or their loved one. Some people find that the case management process has been an empowering and enabling one and they reach a point where they no longer need that type of support. Others, like Ruth may have experienced some level of empowerment but their individual circumstances are such that they will always need case management support, particularly as their circumstances and their caring capacity changes.

CONCLUSION
The cultural shift in disability and healthcare to client-directed support is a positive one that can benefit many people, but it does not work for everyone. It is however, a goal of all interactions between workers and people with healthcare issues or disabilities. As poet, William Ernest Henley (1888) wrote, don’t we all wish to be the “master of our fate” and “captain of our soul”? There are many situations where clients can achieve this with skilled and timely support, or entirely on their own. However, when life and circumstance overwhelm, case managers step in to provide direction, knowledge and support for people to become, as much as possible, their own masters once again.

ACKNOWLEDGEMENTS
Many thanks to Sue Lukersmith (PhD candidate) for her reading and contributing comments for the chapter and to Cheryl Jones (case manager) for her perspectives on the role of case managers.
MEIKLEJOHN

REFERENCES


Jane Meiklejohn BAppSc(OT)
Occupational Therapist and Case Manager
NSW, Australia
SECTION 4

WAYS FORWARD
ALFRED DE LEEUW AND CHRIS ATKINS

17. CONSIDERATIONS FOR QUALITY OF LIFE

Always Looking from the Outside in

INTRODUCTION

Most parties involved in community-based healthcare are concerned that people with ongoing healthcare concerns and/or disability receive the best possible healthcare and achieve wellness and happiness in the way they live. However many different perspectives can be held by people with disability, their families, their paid carers and health professionals about these issues. Decisions about Quality of Life (QoL) can trigger strong emotional responses, making for difficult conversations and often much frustration. Discussion grew out of observations of community-based healthcare by the authors, especially in situations where people are cared for by paid carers rather than their family. In the section Whose choice? (see below), the first two authors have a discussion about tensions and issues regarding QoL for people with developmental disability. Chris is a nurse consultant who also has a family member with a severe developmental disability and Alfred is a community-based physiotherapist who works with people with developmental disability, their families and their carers in family and group homes. The discussion was based on their broad professional experience across a range of different settings, both private and public and reflects their differing personal perceptions.

QUALITY OF LIFE AS A CONCEPT

Quality of life is defined as an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. (WHOQOL Group, 1993, p. 153)

QoL is “a broad ranging concept, incorporating in a complex way the person’s physical health, psychological state, level of independence, social relationships and their relationship to the salient features of their environment” (WHOQOL Group, 1993, p. 153). Within any person’s life, all domains (impairment, general health, gross motor skills, self-care/fine motor skills, speech/communication, integration/participation, QoL, and caregiver issues) are important but QoL can be considered as the most important (Vargas-Adams & Martin, 2009). Measurement of this “elusive concept” is problematic, not least because of the paradox that in many instances, people with severe and persistent disabilities report that they experience

D. Tasker et al. (Eds.), Community-Based Healthcare: The Search for Mindful Dialogues, pp. 141-148. © 2017 Sense Publishers. All rights reserved.
a good or excellent QoL when to most observers these individuals may seem to live an undesirable daily existence. Whose perceptions matter? Albrecht and Devlieger (1998) found that QoL is dependent upon finding a balance between body, mind and spirit in the self and on establishing and maintaining a harmonious set of relationships within the person’s social context and external environment; in other words, steady and competent carers, visiting friends and family. Again, the question must be asked, whose perceptions matter?

QoL is increasingly being measured to rate the services that are being employed to maintain or enhance the QoL of a person or to try and capture the changes in QoL over time. Each QoL instrument proposes a set of attributes, which is thought to be of importance to the individual or policy maker. There are few health related QoL (HrQoL) instruments that can include people who are not able to communicate. In these situations, health carers and care coordinators have to rely on parents’ and carers’ proxy perceptions of HrQoL. McVilly, Burton-Smith, and Davidson’s (2000) study of the concurrence between subject and proxy ratings of QoL for people with and without intellectual disabilities reported that over or under estimation of ratings by proxies was minimal. However, White-Koning et al. (2007) also reported that parents of children with chronic conditions proxy-report lower QoL than the children themselves especially in the subjective domains. Differences between the ratings of HrQoL of children by their parents and health professionals has also been documented, for example, health professionals often over estimate HrQoL, particularly with regard to the subjective attributes of emotion and pain/discomfort (Morrow, Quine, O’Loughlin, & Craig, 2008). In this study, the health professional (paediatrician) assessed the child to have less pain/discomfort in comparison to the parents. Disparities in perception occur between everyone concerned.

THE QUESTION OF CHOICE: WHOSE CHOICE?

In the following conversation, the first two authors approach some uncomfortable issues that arise around the concept of choices for people with intellectual and physical disability and how differently people can think and feel about ideas. Some of that discomfort and uncertainty can occur because of the differing experiences that people have and the lack of knowledge we inevitably have about other people’s experience. The difficulties in providing good levels of care, given both human and economic constraints, also contribute to the uncomfortable nature of care issues being discussed. While this discussion seems to be just about living, there is an obvious connection to providing healthcare in all its myriad habilitative aspects.

Chris My brother is 55 years old and has a severe intellectual disability. He has recently moved into a group home after 20 years at home with Mum and 35 years in a large institution. My mother is 83 years old. During a recent conversation, I asked her if she was watching “The Dream House” on TV (a program about young people with intellectual
disability who move in together and gradually sort out their living arrangements and relationships). She said “I couldn’t watch that. It would be too upsetting. In the show, the people get quite upset about things but Kevin wouldn’t know what was happening”. However, a week later, I asked her how he was going in the group home. She said “I think he’s wondering where all the people are. I just want him to be happy and well”.

Alfred So Mum went along with the decision for him to go into the group home? I as a health professional would have felt that it was important to make available to Kevin the opportunity to have access to community, have choices about things like what he would like to eat or what clothes he would like to wear. That is my idea of quality of life.

Chris I don’t quite know where to begin. I have been very upset by this one size fits all philosophy of group home placement. I feel furious about suggesting that my brother can make choices, even choices about food and clothes because I think that we are imposing an ideology that does not allow him his disability. He has a very severe intellectual disability.

Alfred … his idea of who he is, as he is?

Chris Yes, staff might suggest that he is making choices when he cannot. I feel that offends his humanity – as he is.

Alfred You think you’re offering him a choice by moving him into a group home without really giving him the choice of staying in his familiar surroundings?

Chris I find it curious too that they are closing down large institutions and setting up “group homes” which may be smaller but still have institutional thinking at their core.

Alfred I agree. I have come across the situation where a group home carer who took a resident out to the movies had to bring him home in the middle of the movie because that staff member had to be back to the group home at 2pm for shift handover. This is not an isolated incident. Limited staff numbers often mean that residents of group homes or nursing homes cannot do many of the activities we all take for granted.

Chris It’s everything. Can I have a shower in the morning? Staffing numbers can also actually stop people going out into the community if their disability support worker is not available (DSWs). What choices or preferences do they really have? How real are those choices?

Alfred Many people with disability can’t speak. Any relationship between the person being cared for and their carer or DSW depends on the relationship between them. Ideas about QoL cannot be imposed via a
generalised prescription because each interpersonal interaction will be unique to the people concerned. It is how an experience makes you both feel.

WELLBEING AND QUALITY OF LIFE IS LIKE A BUBBLE

QoL can be seen with a tick box mentality – tick some boxes and get accreditation. We ask, “Who determines what the boxes are and whether they get ticked or not?” The term QoL is like a soap bubble with many colours. Try to separate one colour from the other and before you know it, it pops. We would like to pose the question, “Can clients whom family and DSWs perceive to have a poor QoL still achieve improved wellbeing?” Wellbeing may not mean that all of one’s needs are met or that one’s full potential is being achieved. People who cannot communicate easily have to rely on others to interpret for them. Those “others” will then decide what the best components/attributes might be to help achieve wellbeing for “the silent one”. Such “others” are generally family, DSWs and health professionals.

There can be wide variations in the subjective domains/attributes of emotions and pain/discomfort when people try to ascertain how these domains influence the wellbeing of a third person who cannot communicate. In such situations, who or what drives the decision making about what might be needed to support the wellbeing of the client? Is it the family who might have opted for early permanent out-of-home care and who are not responsible anymore for the practical day-to-day care or is it a DSW who is responsible for the client’s everyday care and knows them very well? Is it the health professional who visits? Is it a case manager (such as in the National Disability Insurance Scheme [NDIS]) who makes decisions about funding packages? A good starting point for coming to some sort of agreement regarding the components of care that can facilitate wellbeing for a third person is an awareness of our own background. Health professionals and case managers may be very goal-orientated in an approach driven by the aims of funding bodies and the need to show progress/proof. In contrast, families might base their decisions about care on past successes or on people with similar issues as their child. DSWs might think about wellbeing in more practical ways, for example, how can we make caring easier? Currently, the “person responsible” makes the ultimate decision and this probably cannot change (from a legal position). However, some of the tensions could decrease with better use of shared decision making (Elwyn et al., 2012), supported decision making (Disability Services Division, 2012), and/or future care planning (Kearney, Atkins, & Bateman, 2012).

Wellbeing cannot be captured in the achievement of goals alone, a program or treatment approach. It is an ongoing mutual process in which the client is both the leader and the focus of a team, working together with different types of expertise, and able to change direction whenever the client shows a new direction is needed.
VIGILANCE FOR QUALITY OF LIFE

Vigilance is necessary at both the individual and the system level and includes the everyday support needed by clients and the governance required to ensure that this occurs. In an HrQoL study, De Leeuw and Atkins (2014) found that families essentially wanted their children to be happy and comfortable. For example, in a recent conversation with a parent, she asked how she could teach DSWs to be vigilant about her child sweating under his doona, a problem she had noticed when visiting. Many health colleagues have tales of the neglect that can occur when DSWs do not notice what they see daily, and further stories about unnecessary presentation to hospital or arriving at the emergency department for urgent and late treatment. In another conversation with a nurse manager, she indicated that clients were thriving since DSWs had learnt how to monitor their comfort and happiness more carefully. This led us to take another look at how being “happy and comfortable” could be related to the concept of vigilance regarding QoL for people with chronic healthcare concerns and decreased ability to communicate. Some examples are included in Table 17.1.

Most people with a severe physical and intellectual disability do not have the capacity to direct their own care, being mostly non-verbal communicators who require family and DSWs to enable them to lead happy and meaningful lives. Health professionals and DSWs rely on knowing clients over time to understand their usual state of being, for example, regularity of coughing or spasm, and their communications, how they indicate preferences, comfort and discomfort. How do they get to know them? We contend that such intimate and personalised knowledge can only be gained by being “in their space” but this needs to be a space where family, DSWs and health professionals are sensitised to the importance of happiness and comfort. Entering this space can begin with thoughts such as “something’s not right, or “he’s not himself” and will require a knowledge of what might be wrong, or at least a referral to someone who might know. Such knowledge is gained through experience, time spent with the client (not hours/days but months/years) and ongoing learning (Atkins, 1998). Signal detection theory (Latall, 2012) is adding to the body of knowledge about teaching vigilance with ways to increase attending: seeing, understanding and acting (see Table 17.1).

Governance for Vigilance

The goal of governance is ultimately the wellbeing of the client. Governance is laid down in the policies and procedures of organisations and the guidelines of national monitors, e.g. NDIA, Ombudsman, based on evidence-based best practice. Strong emphasis is put on the importance of decisions being made about the wellbeing of the client, within a person-centred framework. When the client is living in a group home and is unable to communicate their wants and needs, a consensus should be arrived at among relevant stakeholders for a desirable and equitable level of wellbeing. Governance in such situations is not so much about reaching a certain
goal as it is about the process that is involved, without a time limit. The most important point about governance is ensuring that it is more than just having the paperwork in order – it is vital to wellbeing that the activity actually occurs.

Besides the policies, procedures, supervision and training which lay down a framework of behaviour in regards to the direct care of clients, vigilance extends well beyond their personal space to how we help them present themselves to the outside world, e.g. being well dressed, wheelchair clean, bedroom clean and dust free, house well maintained, transported with care, etc. We need to be directed by an ability to put ourselves in their shoes and ask ourselves, “What if this was my house, my wheelchair, my meal, my transport, my day program, my bedroom, my bathroom, my healthcare, MY PARTY? How would I feel?”

Table 17.1. How happy and comfortable am I?

<table>
<thead>
<tr>
<th>How comfortable am I if:</th>
<th>How happy am I if:</th>
</tr>
</thead>
<tbody>
<tr>
<td>My head is full of cradle cap?</td>
<td>Any of these uncomfortable things are happening?</td>
</tr>
<tr>
<td>My eyes are infected?</td>
<td>Any are left until there is a crisis and I am hospitalised?</td>
</tr>
<tr>
<td>My nose is running?</td>
<td>I have to go to hospital to have my G-tube/catheter replaced?</td>
</tr>
<tr>
<td>My skin is dry/cracked?</td>
<td>I have moved away from all the people I have known for years?</td>
</tr>
<tr>
<td>I’m constipated?</td>
<td>I am introduced to activities which increase my spasm?</td>
</tr>
<tr>
<td>My feet are covered in fungus?</td>
<td>I am subjected to music that offends my hearing?</td>
</tr>
<tr>
<td>I’m sweating, I’m shivering?</td>
<td>I am sat in front of a TV/computer when I have cortical blindness?</td>
</tr>
<tr>
<td>I am in pain with arthritis?</td>
<td>I have my food spoiled with all these pills I have to take?</td>
</tr>
<tr>
<td>I’m coughing all the time?</td>
<td>People walk into my bedroom when I am being changed?</td>
</tr>
<tr>
<td>My scoliosis is increasing?</td>
<td>People don’t knock on the door before they enter my house/room/space?</td>
</tr>
<tr>
<td>My spasm is not controlled?</td>
<td>I have to go to all these doctor’s appointments to find out the obvious?</td>
</tr>
<tr>
<td>I’m choking on my food?</td>
<td></td>
</tr>
<tr>
<td>I have not been moved in the last two hours?</td>
<td></td>
</tr>
<tr>
<td>I am moved too quickly without me being able to anticipate the move or my muscles have not been given enough time to respond/relax?</td>
<td></td>
</tr>
<tr>
<td>My carer’s cold hands or hard hands grab me without me being able to anticipate what is next or know what is expected of me?</td>
<td></td>
</tr>
<tr>
<td>My incontinence pad is soiled for long periods of time?</td>
<td></td>
</tr>
</tbody>
</table>
CONCLUSION

QoL is always a complex ongoing process, rather than an outcome. Relationships are essential to that process but perceptions of others’ QoL remain in contention. With the changing landscape for services for people with disability, there are inevitable concerns about vigilance and governance. This chapter has raised many questions, many of which cannot be fully answered. However, by highlighting their presence, healthcare workers may have a better chance of achieving improvement for their clients’ quality of life or at least continuing to work towards that aim in a productive way.

ACKNOWLEDGEMENTS

The authors would like to acknowledge the contribution of people with disabilities and their families; in particular, Joan Moroney and her son, Kevin Atkins.

REFERENCES


Alfred De Leeuw  
Physiotherapist  
Penrith, NSW, Australia

Chris Atkins RN PhD MACN  
Educator  
Royal Rehabilitation College  
Ryde, NSW, Australia
18. COLLABORATING IN COMMUNITY-BASED HEALTHCARE

Mindsets for Relational Practice

INTRODUCTION

Healthcare for complex problems commonly involves health professionals collaborating with clients and their families, as well as collaborating with each other. However the team contexts within which such collaborative care is provided, varies. On one end of the spectrum are teams with a stable base of health professionals who have worked together for a long time and have a strong sense of *teamness*. By providing collaborative care to many different people in different situations, the health professionals in such teams will have developed particular ways of working together and a shared history of practice. While health professional membership of these teams may be relatively stable, their client population may constantly change in accordance with clients’ progress or changing circumstances. Rehabilitation teams providing inpatient services are an example of such teams. The nature of collaboration in rehabilitation teams tends to be viewed in relation to how the health professionals work together, as evidenced by the myriad of prefixes (multi-, inter- and trans-) and varied labels (professional and disciplinary). While patients are undoubtedly the focus of collaboration, their role in the collaborative entity can be ambiguous. Are they part of the team? If so what does their involvement entail? What scope do they have to help develop team processes and decide meeting times? Do they have input into the ways the team members work together? In many instances the need to adjust to their newly altered bodies and emotions, daily challenges and healthcare requirements, puts patients beyond the scope of contributing readily to team process and the maintenance of *teamness*. Thus, in these situations, they cannot be automatically considered as team members.

In contrast, at the other end of the collaborative care spectrum, are teams where clients and families are clearly integral members of the team and not just the focus of care. The team members retain, maintain and develop their control and responsibility for team functioning. An example of such entities are *family-created care teams* where clients and families initiate and form the team and have input into when the team members provide home-based care and where they meet to discuss issues with the people at home (see Tasker & Jones, 2014). The health professional membership of such teams may be particular to the client, and each

D. Tasker et al. (Eds.), Community-Based Healthcare: The Search for Mindful Dialogues, 149-156. © 2017 Sense Publishers. All rights reserved.
client is likely to have a unique team of family members, carers and health professionals. Members of family-created care teams are unlikely to have a shared history of working together in different contexts and few opportunities to get to know each other outside the context of a particular client’s care. While clients and families are clearly members of the team, the broader team may be less obvious to those working within it. How many different people are involved? What organisations do they represent? When do they provide care? What does this care look like? How does everyone work together?

It is within the context of such family-created care teams that this chapter is situated. This is not to say that such care teams occur in all community-based healthcare but they are becoming increasingly common as families strive to care for their members at home. In Australia, recent policy support, for example palliative care initiatives and the introduction of the National Disability Insurance Scheme, highlights the need to better understand the nature of collaboration in such teams; all of which aim to support client choice and autonomy.

A TALE OF TWO THESES

The structure of this chapter results from conversations about key findings developed through our respective PhD research projects. First author, Anne’s research explored the concept of collaboration and experience of collaborating in rehabilitation teams (Croker, 2011). She identified five endeavour dimensions of collaborating: engaging, entering, establishing, envisioning and effecting. These endeavour dimensions of collaborating provided the basis for extending the PhD findings of second author, Diane. Diane’s thesis explored the relationships that can develop between community-based physiotherapists, their clients, families and carers/support workers and the meaning that all of these people can ascribe to those relationships.

In the resulting conversation between Anne’s endeavour dimensions of collaborating and Di’s relationship dimensions of mindful dialogue we focused on the nature of collaborating to provide person-centred care in the home. Through our conversation we aimed to ensure that client needs in terms of choice, individuality and meaningful participation in life, as advocated by the World Health Organization (WHO, 2001), remains core to the purpose of everyone’s collaborative practice.

EMBRACING A MINDSET

“Person-centredness” and “person-centred thinking” can be thought of as a philosophy, a way of thinking or mindset which involves viewing, listening to and supporting a person with a disability, based on their strengths, abilities, aspirations and preferences, to make decisions to maintain a life which is meaningful to them. Such a mindset or way of thinking is essential to the development of a “person-centred plan” and the provision of “person-centred support.” (Richmond Psychiatric Rehabilitation Australia, 2013)
A key to collaborating in a family-created care team is a person-centred mindset. Such a mindset allows health professionals to enter the clients’ world and truly listen to their needs, wants and life stories. Embracing this mindset enables a strength of commitment to the person and an honesty and authenticity of approach that is important when visiting and relating to people in their own homes. As the client and family are included in the collaborative process, the mindset of the client, family and carers (who spend the most time with clients) is equally important to that of healthcare practitioners.

Of central importance within the mindset of team members is the power differential occurring between healthcare practitioners and clients. With regard to the control over “who visits”, “when they visit” and the nature of healthcare interactions with the client, clients and families have more power in their own homes than when healthcare interactions take place in healthcare institutions. Accordingly, healthcare practitioners may find that such a loss of power is accompanied by a sense of instability of “being always the guest” and “being always on the client’s territory”. Heckman and Cott (2005) described this phenomenon as “entering a different world”. Such a lack of control can be reinforced when processes and outcomes in community-based healthcare are different to what they may have been used to working with in more formal organisational settings. On the other hand, when community-based health professionals are witness to the “chaos of family life” they may be brought into the inner circle of trust within the family and become “one of them” for that visit and perhaps on-going visits (Tasker, 2014, p. 207). The privilege of such acceptance can be welcomed by experienced healthcare practitioners.

ENTERING INTO THE FORM AND FEEL OF A FAMILY-CREATED CARE TEAM

All the world’s a stage,
And all the men and women merely players;
They have their exits and their entrances.
Shakespeare41

People contributing to clients’ healthcare in family-created care teams range from health professionals representing different professions, carers providing daily care or family members and friends with particular skills to offer. Included within this mix can be private, public, volunteer or compensatory frameworks of service provision. The team’s make-up reflects the situation and needs of the client, accessibility of funding and the availability of people around them. There is no “one size fits all” team. The notion of collaborative arenas (Croker, 2011) is a useful way to engage with the complexity of entering family-created care teams. Collaborative arenas highlight the possible varied nature of “teams” in rehabilitation. Integrated collaborative arenas are those where team membership is relatively stable and where guidelines exist for team processes. Leadership is clear, team members are explicitly appointed and there is a designated budget. In contrast, intersecting collaborative arenas exhibit fluidity of team membership
with no set processes for communication or clarity of leadership roles. Teams can have characteristics of both arenas. Locating family-created care teams within the notion of collaborative arenas provides an opportunity to recognise the varied forms of teams and the issues faced by health professionals entering and working within them.

Family-created care teams are often located within an integrated collaborative arena. An example of such a team could be when a person departs from hospital acute care, and is supported by an outreach team or transitional care team chosen by the family or provided from the hospital. These team members come out to the person’s home to deliver care in a carefully coordinated manner. In such integrated collaborative arenas, health professionals beginning in the team may have planned entry, being introduced to the other team members during regularly scheduled meetings, perhaps away from the client’s home, with opportunities to be oriented to how the team works.

In contrast, an example of a team working in an intersecting collaborative arena is one where there is a mixture of healthcare practitioners from both private and public sectors who may not work together for any other clients; they may meet around the kitchen table in the client’s house with the family and carer closely involved in the meeting or passing each other on the way in/out of a client’s house. Healthcare practitioners working in these situations may need to be personally proactive in getting to know each other to establish a feeling of teamness. This may involve meeting and chatting informally over coffee or connecting by phone.

Common to all health professionals beginning in new teams, regardless of whether the team is an integrated or intersecting collaborative arena, is the need to negotiate entry into the client’s “space”, while simultaneously entering into an existing or new “team” of carers and other health professionals. Using the metaphor in the quote above, these health professionals become “merely players” on the client’s stage and may not all appear together. The negotiation of these two entries, while tricky, can be facilitated by making available, personal and emotional personas within therapeutic interactions as people get to know one another. The sense of teamness between health professionals and between all members of the family-created care team can be important for situations where it may be necessary not to get “caught up in family dynamics” that might be peripheral or damaging for the client’s collaborative healthcare. The sense of teamness can help the team remain focused on the client at its centre.

ESTABLISHING WAYS OF COMMUNICATING AND WORKING TOGETHER

Treat every connection, communication and collaboration as part of a continuous relationship (Chandler McDonald, 2015)

Establishing ways of communicating and working together to provide person-centred collaborative care in the client’s home requires consideration of a number of factors including:

- when to hold team meetings to ensure maximal participation
how to ensure that the client’s voice is heard amongst competing voices and
how to communicate between meetings while remaining true to the client’s
philosophy and family being involved in updates and decisions.

Ensuring that clients’ voices are heard in structured communications can involve
formal meetings with them and all those involved with the client’s care, as well as
written reports being available to clients and families. There may be situations
when the healthcare practitioners decide they need to have conversations away
from the client and family. While a number of these conversations may occur with
permission from the client and family to communicate about their treatment with
other healthcare providers (What are we going to do next?) they can also be about
exploring emerging issues (Can I discuss something I am concerned about?) and
about supporting other healthcare practitioners in difficult clinical settings (How
are you managing?), clarifying how to work together (Our roles are overlapping in
a manner that we need to discuss?) and getting to know colleagues (I don’t know
you very well, I am new on the team? and I need to get to know where you are
coming from and how you work?). Such informal conversations may be held via
the phone, over coffee, on the verandah or out at the roadside while practitioners
are arriving and leaving. Important for such communication are issues of being
transparent to clients and families and staying true to the team’s philosophy for
their involvement, and not allowing splintering of the team into subgroups of those
“who know something” and “those who don’t”.

ENVISIONING CLIENTS’ FUTURE DIRECTIONS

No human being is constituted to know the truth, the whole truth, and nothing
but the truth; and even the best of men must be content with fragments, with
partial glimpses, never the full fruition (William Osler*).

Envisioning clients’ future directions in family-created care teams for person-
centred care in the home can differ according to the shared history of those
working in the team. Teams where healthcare practitioners have an established
history of working together for a number of different clients may be able to draw
on previous experience. Examples of such formal or informal teams include
outreach rehabilitation teams or local private practitioners in a particular
geographical area. Collective understandings arising from experience over time
may be used as a starting point for listening, discussing and negotiating directions
for future care with the current client and family. Teams without a shared history
(who work together for a particular client rather than a number of clients) may
need to have explicit conversations that enable individuals to draw on their
personal experience of what is possible. However, it is important for both styles of
teams to embrace the mindset of person-centred care which allows “one’s own
perception of what is a good outcome” from a practitioner’s point of view to be
challenged or integrated with what the client and family perceive as a “good
outcome”.
The envisioning of a client’s future directions does not happen in isolation to the client and family. Wherever possible, decisions need to be made in the presence of the client. Where the clients’ cognitive ability does not allow full participation in the decision-making process, the family can become the client’s proxy in that decision-making process. However, it is often possible to adjust this process to include such clients even if it is only for part of a meeting. At times the future direction envisioned by clients may be unexpected in their simplicity of desire (such as a favourite item of food or positioning of a piece of furniture) or they may be outside the area of expertise of the current team members and require broader collaboration. Envisioning clients’ future directions in their presence and with their assistance can often involve healthcare practitioners negotiating elements of tension between “professional views” and “personal views” as well as tensions between family members coping with the power dynamics of their particular family group. Judgement as a health professional, and reaction as a human being responding to the client as a person who is trying to tell you what they want, add layers of complexity to the process of envisioning. Managing such tensions can be an important part of keeping the client as part of the collaborative process.

EFFECTING CHANGES IN PEOPLE AND TEAMS

Coming together is a beginning; keeping together is progress; working together is success.
(Henry Ford)

Providing long-term, person-centred healthcare in a client’s home can be challenging. Beyond dealing with the nature of their physical impairments or medical conditions (which may be associated with emotional, behavioural and social issues), health practitioners may feel isolated, without the collegiality of having other healthcare practitioners in corridors or tearooms down the hall. There is a necessity for each healthcare practitioner in community-based settings to take care of themselves and their colleagues in the light of recognising when they or their colleagues are experiencing burnout and are perhaps talking negatively about their clients and families. Such talk can be an indication that team members are losing their humanity for the client as a person. Integral to effecting changes in people and teams is the need to retain positive human regard for people. To keep clients a part of the collaborative process, conversations with colleagues need to frame clients and families in a positive humanistic light and avoid negative personalised comments. Rogers (1989) described this as a “positive unconditional regard”, the relational situation, which occurs when a therapist holds the client in high regard all the time. Personal commitment is required to “not change” from being person-centred and to support colleagues in maintaining their continuing positive regard for the client. At times managing this positive regard can require sensitivity as to when it is time for someone to move on from the team.
BEING MINDFUL, STAYING ENGAGED AND BEING RESPONSIVE

The meta-behavioural characteristics of being mindful, staying engaged and being responsive (Tasker, 2014) are core attributes for all key members of the team. Through these important human processes, teams can create and maintain a caring circle of collaborative person-centred healthcare where the client and family are integral to conversations and decision-making. Being mindful involves the individual practitioner developing and maintaining an evolved degree of dialogical sensitivity to “the other”, through,

... a variety of means to enhance their ability to engage in moment-to-moment self-monitoring, bring to consciousness their tacit personal knowledge and deeply held values, use peripheral vision and subsidiary awareness to become aware of new information and perspectives, and adopt curiosity in both ordinary and novel situations (Epstein, 1999, p. 2).

Staying engaged requires that people interact and work with an attitude of receptive attentiveness and presence in order to promote trust and develop reciprocity. Healthcare is not “done to” people but is “done with and for” them. The client has to be an integral part of contributing to the healthcare practitioners’ learning and development. Responsiveness involves being able to not just respond to issues but rather, respond to people and their concerns (Tasker, 2014).

CONCLUSION

Community-based healthcare practitioners need to work together to protect the essential nature of community health, thus allowing people to maintain their individuality and have choice and meaningful outcomes in the way they live their lives. Although collaborative practice in family-created care teams can be difficult to see, it is necessary to understand this phenomenon, in order for healthcare practitioners to more easily transition between the different styles of collaborative practice required when caring for people in their own homes (in a family-created care team) compared to when the client is receiving healthcare in an institutional setting.

ACKNOWLEDGEMENTS

There were many participants involved in the two thesis projects sourced for this chapter. This chapter could not have been written if not for them.

NOTES

ii http://www.poemhunter.com/poem/all-the-world’s-a-stage
iii http://www.brandquarterly.com/flat-world-navigators-winning-global-dace-race
iv http://www.brainyquote.com/quotes/quotes/w/williamosl133881.html
v http://www.brainyquote.com/quotes/quotes/h/henryford121997.html
REFERENCES


**Anne Croker PhD**
The University of Newcastle, Australia
Education, Practice and Employability Network, Australia

**Diane Tasker PhD**
Education, Practice and Employability Network, Australia
19. A FUTURE PATH FOR HEALTHCARE IN THE COMMUNITY

Creating a Mindful Crucible of Healing

INTRODUCTION

Medical science forever forges ahead, much to our benefit and gratitude, revealing new and better ways of practising the healing arts. However, the shape it takes when being dispensed by its knights in shining armour, tends to continue to be practitioner-centric. This is despite the fact that clients are becoming more medically literate, uncomfortable with the old-fashioned hierarchies and attitudes, and eager to take an active and self-referential approach to their medical care. This chapter describes a possible evolutionary trajectory for health practice to unfold into the future, while reflecting and protecting the changing needs and wellbeing of clients and doctors both.

THE PAST

Growing up as an Australian child in the fifties and sixties meant growing up with a very different experience of medical care to that we now experience in the early decades of the twenty-first century. The general medical practitioner (GP) was almost an honoured member of the family.

He (there were of course many “shes” in practice, even then, but for the sake of convenience we will stick with the masculine pronoun) usually worked on his own, or at most with one or two close colleagues, often practising out of someone’s family home in the suburbs.

You could usually rely on getting your own GP every time, except if he was away on holidays. But GPs did not seem to go away on holiday much … certainly no more than the rest of us. They were too busy. They worked all sorts of insane hours and could be counted on for home visits, delivery of babies, visits to hospital and even attendance at funerals. Their children hardly ever saw them. They were respected for their knowledge, their expert authority usually went unchallenged, and the community at large accorded them a high degree of sapiential authority.

A GP was considered to have the wisdom to give life advice as well as medical treatment. We showered them with fruit cake and bottles of sherry at Christmas and we obeyed implicitly everything we were told to do. Even the act of arriving in the surgery waiting room was imbued with a sort of reverence.
We would sit still
and be on our best behaviour,
not banging our shoes on the chair leg,
not crying.
not punching the nearest sibling
or whingeing about going home.

If we had done any of these terrible things,
and others besides,
the receptionist would glare coldly at us
and our mothers would die of shame.

If we were missing a day of school
because of some ailment
we trembled
lest the doctor prove us malingerers
to our suspicious mothers.
The doctor sees all, knows all.

Even highly educated clients thought twice about challenging the opinion or orders of the doctor. He was harassed, he was tired, but he was right. Our parents paid for the attention of the doctor because it was indispensable. To go against that expert authority would be like refusing the help of a benign deity. It would just be stupid.

THE PRESENT

Today doctors are ruled by a whole other set of economic realities and clients are a different breed of people. Doctors are mostly paid by third party insurers. Those insurers agree to pay for certain treatments and not for others. The doctor will go poor if he insists on behaving like the rugged individual he used to be.

Clients are nearly all internet savvy. While all that can be learned from the internet cannot be relied upon, there is enough reliable information that even the most poorly educated client can probably explain his own condition reasonably well. What is more, he does not hesitate to tell the doctor what he “knows” or believes about his condition and its treatment. One of the reasons this has become a more prevalent client behaviour has been the fact that doctors no longer offer their clients the same degree of service they used to.

For the sake of economy most GPs are now ensconced in large group practices. This means that they can be covered by other GPs if they are away. Doctors these days appear to be away from their practices a lot more often than did the GP of yore. You could say that this means either than doctors earn a lot more than they used to, or that they look after their own health much better now than they used to. Either way, clients cannot count on seeing their GP of choice any more. The relationship has become weaker. Because of high insurance premiums and a climate of legal challenge around
medical practice, doctors are now more limited in the scope of their activities. Most no longer deliver babies.

Many previous areas of GP practice are now referred off to specialists. Many doctors do not do home visits at all, and others ensure they can afford to send two people on home visits for safety’s sake. Our old-fashioned doctors did not worry overly about being safe as they did their rounds … who would hurt the doctor?

No longer is the doctor a minor deity;
he makes mistakes,
he is human,
his knowledge is limited
in a field of constantly expanding expertise
where no one person could hope
to encompass all the medical knowledge available
to the full range of practice.

Today’s doctor can be challenged and questioned.
Today’s clients are internet-literate
and make use of the knowledge to be found there.
Today’s clients know more
and do more challenging
and questioning.

Today’s clients often choose to be non-compliant. This may be because they do not understand the doctor’s instructions in ways that are self-referentially meaningful, or perhaps they just straight-out disagree with the advice given by the doctor. Not only is it no longer considered stupid to question medical advice, but everybody seems to have a story where someone they know nearly died because of being given the wrong medical advice.

The description and comparison above is no doubt much too simplistic. There will always be exceptions to the pattern described. The trend we see emerging however begs us to make some changes in medical practice so that in the future doctors and clients can assimilate and develop practices and attitudes that better benefit and reflect the needs of both groups.

THE FUTURE

We can’t turn the clock back. As ever, our only choice is to move forward and it is not obvious which direction to take. Technology has brought wonderful gifts to medicine, but it has not solved the problems of the chronically ill client as much as it has created more chronically ill clients. Many who might have died before life-saving technological, surgical and pharmaceutical fixes were available, now live on but with a reduced quality of life. Chronic conditions that most feel would be preferable to death, have to then be managed by the grateful client every day. For example, cancer clients
can often now survive with on-going pain and disability from treatment and the fear of recurrence.

How can we create a medical service that meets the needs both of our newly enfranchised clients and of practitioners who may feel dispirited and powerless in the face of client empowerment and economic rationalism? What do the users and providers of medical practice need to work toward? What should we be trying to create? Chronic disease forms the bulk of general practice these days, and chronically ill clients need to be empowered with knowledge and with respect to work with their healthcare professionals to create a management plan that sits in a satisfying way with the client’s life expectations and values.

Doctors for their part want clients to participate responsibly in the management of their own condition and clients want to be part of an equal partnership with their doctors. Clinicians and clients alike pay lip service to the idea that what they would like in their medical interactions is to be able to participate equally and respectfully in a mindful community of practice, learning to work collaboratively across disciplines and with clients. What would such a mindful practice community look like?

The concept of a practice community when applied to the medical relationship is perhaps a relatively new and interesting one. In older times, one health professional engaged with one client and attempted to turn the tide of disease in the client. The power lay with the professional and the requirement for obedience and compliance with the client. It was an unequal relationship, entered into with the idea that the client could and would be cured of whatever ailed him, and so the temporary loss of identity to the client as he submitted to the instructions of the health professional seemed an acceptable trade-off in most clients’ eyes.

There was no need of a practice community when one professional was thought to be able to do the job, and when we are talking about treating an acute or curable bout of disease, it is still conceivable that one appropriate professional will probably be able to bring about that cure. However, where chronic and complex disease is concerned, and cure is not an option, the responsibility for managing the client’s illness diverges out to include people other than a singular doctor or health professional. The term “community of healing” comes into play in such cases. A community of practice for a client with chronic pain, for instance, might include the doctor, a physiotherapist, a psychologist, a dietician, and of course the client herself. It is the client who has to live with the disease and it is her life goals that will determine what management plans are useful to her and which ones are not.

Such a practice community needs to be constantly mindful of collaboration with each other and with the client. It is much easier to be a lone practitioner doing one’s own thing than it is to work in genuine respectful collaboration with a group of other practitioners and a client and maybe even the client’s family or employer. Research in the field of participatory medicine would appear to apply to the goals of a practice community, where the client is considered to be a participatory part of the management team.

The following cites the findings of a search of thirty articles published in the Journal of Participatory Medicine over the previous two years, using search terms such as client empowerment, collaborative practice, mindful practice, medical community, medical
Clients expect their views to be treated with respect by their clinicians. Clients would like their views and understanding of the medical situation listened to, before a mutually acceptable shared narrative of illness and management is arrived at. No longer is the view of the clinician the only one of significance in forming a management plan. Shared narratives that evolve into management plans agreed to by both clients and doctors involve a more mindful collaborative approach and are therefore more difficult to forge, but are more likely to be complied with by the client.

Clients need to learn how to talk more effectively to clinicians, and clinicians need to help them do that. Some clients express their wishes better than others. Clinicians must make sure each client can speak up about their own values and opinions. Because of their superior hierarchical position, clinicians must be the ones to reach out to clients and help them speak openly. This will take time and care.

Clients need to develop a more robust sense of their own health and illness and what helps or hinders it. We have become too accustomed to letting a clinician define our state of health for us by reading the results of blood tests, or imaging. Of course it is important that a clinician has access to test results to help him determine what is wrong with a client but perhaps he does not at the same time try to find out what is right with the client, what the strengths are in this particular person that might influence the course of the disease just diagnosed. Clients may have to find ways to narrate themselves to their doctors. How you live, and want to continue living, and what gives you vitality are as important for the clinician to know as are what disease you have. Doctors may have to start allowing time for that to happen.

Clients are known to make their own decisions about compliance based on folk wisdom or personal theory when clinicians fail to offer the opportunity to ask questions or clarify mistaken impressions (Finn, 2014). Older clients have significantly more difficulty taking in instructions and therefore may not understand what the clinician has said (Finn, 2014).

This is truly the decade when patients will take control of their health, given their access to monitoring and communication tools, cutting edge and personalized information, and the power of networking via social media. (Smith, Graedon, Graedon, Greene, Grohol, & Sands, 2013; Harmel & Young, 2013)

Clients will become, have already become, more savvy about their health, gathering information form the media and from social media, researching their diseases, discussing management with other clients. No longer are clients isolated from one another, and having access to a network of information and support they must now move into the role of the “expert client”. In response to this, the clinician becomes a resource rather than the ultimate authority to the client.

Patients will demand guidance, tools, information and data that allow them to be active participants in their own care (Smith et al., 2013). Patients need to take on more
responsibility for their health management, and this will become more feasible with access to reliable information, clinicians prepared to act as resources, and a community of fellow sufferers available online (Smith et al., 2013).

Rogers, Christopher, and Sunbay-Bilgen (2013) suggest that the future will see the development of “e-patients”, defined as those who “actively collaborate to care for others, work with clinicians, shape research, and … are active participants in their own self-care” (p. 1). Empowering patients with all types of resources, be it clinician advice and information or that found in a community of like-minded patients or on the internet, “will require a transformation of the patient’s level of engagement, their relationship with their care-givers, and with their illness” (p. 1).

Professional Responsiveness

Clinicians need to be able to support and value their patient’s access to on-line communities of practice, where families and professionals publish information, share experiences and learn by working together. No longer can clinicians expect to be accorded the position of sole authority over a medical situation involving a live and contributing patient.

Clinicians may be the experts on the disease the patient has, but the patient is the expert on how that disease affects his everyday life. Patient organisations aim to improve quality of life for people and their families by raising public awareness of a disorder, disseminating information and promoting scientific research (Guillamon, Armayones, Hernandez, & Gomez-Zuniga, 2010).

Clinicians should be aware of the need to tune in to different cultural needs, different forms of expression other than verbal and other than in the clinician’s native tongue. Language is a powerful barrier to adequate listening and understanding on the part of clinicians. However, patients speak many languages, and some mindful reflection might help a clinician to read the story the patient is trying to tell even when verbal fluency is denied them. Body language, for example, is harder and takes more trouble to read, but may tell the truth of the matter when verbal language struggles to do so (Nambudiri & Easwaran Nambudiri, 2013).

Clinicians need to be able to accept that non-compliance by patients is not always the result of the patient’s misunderstanding of the doctor’s instructions, being stupid or simply being “bloody-minded” or in need of a psychiatric consult. It may be the result of the clinician not having listened properly to the patient when the latter tried to explain the difficulties he anticipates that he will have with compliance. Finn (2014) reports that much of non-compliance is due to patients not having understood what the clinician said, and having little or no opportunity to ask questions. Clinicians need to accept that all patients deserve full information if they want it. It is not up to clinicians to decide who should and should not be told certain information. “The vast majority of patients want to know everything about their …care, including prognosis” (Staggers, Benham-Hutchins, Goncalves, & Langford-Heerman, 2013).

Clinicians need to be able and willing to check with patients that they have heard what the clinician thought he said … “Do you hear what I hear?” (Barnard, 2014; Sears, Bishop, & MacKinnon, 2014). Effective communication improves patient satisfaction,
accuracy of recall and health outcomes and can protect clinicians from malpractice legislation (Sears et al., 2014). Clinicians need to be able to elicit a patient’s conceptualisation of his illness.

How does the clinician see it? How does the patient see it? The patient may see it differently, and it is the patient who has to take the medicine or get the blood test done, not the clinician. After the advice is given the choice leading to compliance on the one hand or non-compliance on the other lies with the patient.

Clinicians need to base their assessments and management plans on the patient’s “subjective experience-in-the-wild” (Storni, 2010). Clinicians need to understand how a patient’s gender, cultural or social situation might affect treatment decisions and how they are able to work with those clinicians. Clinicians need to understand that their story of the patient’s illness is only one story among many possible narratives. The story presented by the clinician is not necessarily more important or more right than the story told by the patient. When patients are able to participate in the development of personally relevant and meaningful treatment plans, the evidence is mounting that compliance is increased (Finn, 2014).

Clinicians should focus on maximizing patients’ access to them, rather than minimising it. This might mean looking for creative means of access, such as various forms of on-line communication and monitoring. Clinicians need to be more open to seeing themselves as patient advocates. Too often a clinician sees her role ending at the office door. Requests for letters supporting a patient’s position with welfare services, educational, institutional or employment bodies are sparse and limited to the bare medical facts when a little more descriptive richness might make a stronger case and help non-medical professionals understand the patient’s situation more clearly and sympathetically.

Clinicians and patients need to be engaged in exploring pathways that would enable them to work more collaboratively across interdisciplinary boundaries. Clinicians will need to work more mindfully with patients, rather than doing things to patients (Smith et al., 2013). Communication will need to take place on a more level playing field than clinicians are used to. Care plans will evolve from clinician and patient talking collaboratively with each other, not the clinician talking and the patient listening.

Practice Management

Practices (clinicians and support staff) should be able to reflect mindfully and responsibly on the partnership they have with one another and with their patients. Practices can create “participatory villages” around the patients suffering particular diseases, such as diabetes, which will require effective organisation to support clinical changes in practice (Shahady, 2011).

A practice (clinicians and staff) should be capable of working with the patient to develop pathways designed to meet each patient’s individual needs. Practices need to be analysing their systems in order to discover ways in which prevailing organisational arrangements might interfere with an optimal relationship between clinician and patient. For example, scheduling appointments with too short an interval between so that clinicians start to run very late.
Practices may be able to develop greater flexibility in service delivery. Office visits may become less frequent, routine follow-up, repeat prescriptions, review of blood pressure, etc. may be conducted online. This will lower barriers to care (as long as patients are internet literate), be more convenient for patients, and less costly. Access might be mediated by email, web-based secure messaging, videoconferencing, phone calls, text messaging and a bewildering range of e-health applications now making their way into practice and into the consciousness of patients (Smith et al., 2013).

Practices may need to explore ways to keep more collaborative records of medical interactions. These could take the form of shared case notes, the patient contributing as well as the clinician (Smith et al., 2013). Practices may need to be open to a need to change their business model, in the face of changes such as have been sketched out above. There may need to be patient and provider incentives offered for working in this way.

If clinicians are to cut down office visits to a minimum, they will need to keep their income stable in some other way or they will go out of business. The new practice style might attract many more patients, but thought would have to be given to how the clinician is reimbursed for time making phone calls, participating with a patient discussion or attending to routine monitoring online.

Smith et al. (2013) suggest that it may be possible to create a hybrid structure that combines management fees to patients with government third-party reimbursement, with traditional health insurers still used to pay for catastrophic care. Practices may need to invest more in being a centre of knowledge and information, providing a library for patients to use, including e-health applications, to help patients educate themselves and to support the educational work of the clinicians. Practices may learn to participate more actively in educational and supportive roles in their communities.

Such engagement should lead to better tailoring of health services to the needs of the community, and to patient programs within the practice that are based on local knowledge and understanding of needs (Gallivan, Kovacs Burns, Bellows, & Eigenseher, 2012).

CONCLUSION

Together we will explore the possibility of learning to open when we desire to close down, to face with honesty and caring attention what is unwanted and what we habitually reject in ourselves and in others, to be present to others and join with them when we wish to move away. (Santorelli, 1999, p. 2)

From the above it should be evident that we are championing a transformation of healthcare, especially healthcare for patients with chronic conditions, on a system-wide basis, one that will change the way patients live with their illness and relate to their clinicians, one that will change the way clinicians think about and design their practices, and one that will require changes in organisational strategies from practices in the community. Transformation on this level will require a great deal of mindfulness, defined by Jon Kabat-Zinn thus “Mindfulness means paying attention in a particular way: on purpose, in the present moment, and nonjudgmentally” (1994, p.4).
It also paints a picture of a potentially complex but creative relationship forming around a patient. We are accustomed to looking at healthcare as either practitioner-centred, or patient-centred, or even as systems-centred. From the wide range of factors highlighted above it begins to look like none of those perspectives alone will quite do the trick.

Santorelli (1999) suggests instead that the systems and supports surrounding the patient-practitioner-systems interaction are like a crucible in which the perspectives of practitioners, patients and systems are all transformed in the heat of mindful action undertaken around the needs of each unique and participating patient. Mindfulness constitutes a discipline and a way to carry the work whenever direction is lost or old patterns re-assert themselves.

Such old patterns may still occur when we find ourselves going back to the old days of the rugged practitioner who expects to be obeyed, the compliant, well-behaved, non-participating patient, and the systems that supported both those roles. A new process could begin with the need to overcome an addictive need practitioners have to be doing something.

Practitioners must enter the world of the patient, learn their language, find their strengths and weaknesses and identify their needs and disruptions before acting … before doing. There is a need to see patients as teachers. The deal could be sealed, the alchemy made complete, when the practitioner and the patient together, supported by the system within which they work, can look unflinchingly and with mutual respect at what has to be done.

Don’t turn your head.
Keep looking at the bandaged place.
That’s where the light enters you
Rumi (Childhood Friends)
(Jalāl & Barks, 1997)

REFERENCES


**Suzanne Alder PhD**  
**Health Psychologist**  
**Bathurst, Oberon, NSW, Australia**
HELEN BUTLIN

20. SOUL-MEDICINE
An Autoethnography

PROLOGUE: A MORNING AT “WORK” – 2007
A young mother sits in front of me. She is thirty-six and has three children under thirteen. She’s in the clinic room, with its narrow cold table and two chairs. She’s just been told she has an aggressive breast cancer. Her breasts will be taken from her within two weeks. Her hair – all her body hair – eyelashes included, will fall out during six weeks of chemotherapy. She cannot work, so she and her husband will be unable to pay their bills.

“How do we tell our children?” She looks at me with tear-filled eyes and numbness clouding her pain.

How indeed? I look at this young mother, arms crossing her breasts, holding them as if for dear life. The breasts that likely nurtured her children and now are to be sliced off.

“Tell them the truth, simply, with straightforward facts and be available afterwards; spend lots of time with them together and individually… Let them come to you with questions … It’s ok to let them see you cry … Show them emotions aren’t something to be afraid of and share yours with them so they’re not afraid of their own.”

No happy ending here. No profound moment of spiritual care shining in the darkness of another’s suffering. Just sitting with them in the fragments of their shattered lives. She makes eye contact as she leaves. “Thank you.”

I leave what I call “work”, which is really a wilderness trek through a ravaged land of broken lives, full of crevasses, landmines, and sudden storms. A land also with bursts of the most glorious sunshine and stunning beauty imaginable as lives break open to deeper truths and radical transformation… Sometimes.

INTRODUCTION
This autoethnography offers an inquiry into the lived experiences of being a single spiritual care practitioner and registered psychotherapist in an urban regional cancer treatment centre in Canada. It tells a “counter-story” (Frank, 1995) of soul in medicine. Autoethnography uses the personal lens based on the understanding that culture is embedded within personal experiences and is perpetuated, resisted or transformed through persons (Ellis, 2004). It can integrate the “heartful” (Ellis, 1999) and the creative (Richardson, 1994) and so the conceptual framework at the heart of this inquiry is “poetic resistance” offered by Kinsella (2006) in her paper entitled Poetic resistance: Juxtaposing the personal and professional discursive constructions in a
practice context. Kinsella (2006, 2012) points to the necessity of poetic resistance in response to current economic and instrumentalist drivers behind institutional and community-based healthcare programs and professional education. Poetic resistance uses poetic reflection to question taken-for-granted meanings, challenge dominant discursive constructions, offer alternative interpretive possibilities, and to gain new insights within a given context (Kinsella, 2006). This chapter engages with this conceptual framework offering a paradigmatic example of the author’s experience developing an outlier service, Soul-Medicine (Butlin, 2015), within a biomedical oncology treatment centre.

Soul-Medicine reclaims ancient philosophical meaning(s) of “soul” in the medical context (De Pablo & Evans, 1994) rather than using its religious reconceptualisation by the medieval-Christian west. It developed from individual counselling and psychotherapy sessions in 2007-2009, engaging in mindful dialogues with clients intentionally attending to their language of soul, spirit and body attuning to what helps to assuage spiritual-existential distress. I learned from these individuals what kinds of soul-full interventions nurture strength, hope and mindful attunement to the present moment in daily life. This can help sustain them in finding some ground under their feet for today, hope for tomorrow and “put fear second” when looking to the future. In 2010 it further evolved into a support group process incorporating poetics, art, music meditation, mindfulness practices with nature and spiritual or wisdom literature. It was titled Soul-Medicine as a means for embodying a form of “poetic resistance” in the institutional, biomedical healthcare context and releasing a submerged language of soul in medicine (Remen, 1996; St. James O’Conner, Lund, & Berendsen, 2013; Vachon, 2008).

Community care contexts, while different from institutional healthcare centres, face similar challenges in offering care at the interface of competing and at times opposing discourses between those driven by biomedicine, policy and economics and those most needed by the person during their encounter with their healthcare practitioner. This chapter fosters dialogue and offers encouragement for kindred spirits in other soul-wearying healthcare contexts. I see the fatigue of heart and soul etched on many faces around me. Their words betoken a soul-pain arising from the ethical confrontations and emotional wounds of attempting to create a soulful, compassionate practice, within the tensions of medical dilemmas and the sheer volume of new clients. Some of the impetus for this autoethnography is to give voice to this. “En-souling” medicine is our shared task (Karolyn, 2006; Reece, 2000).

MEDICALISATION AND “POETIC RESISTANCE”

“Reflecting on practice through poetic form, or what I call poetic resistance, can raise questions about the link between theoretical and practical concerns within the public sphere of professional practice” (Kinsella, 2006, p. 39). In both institutional and community-based healthcare contexts the dominant biomedical discourse can be painfully constraining to both practitioner and client. A client’s vulnerability is exposed through a health issue forcing them to seek healthcare, yet this deeply human
vulnerability tends to meet a dominant discourse inscribing the healthcare conversation through a process termed “medicalisation” (Conrad, 1992).

Poetic resistance carves out a space for alternate discourses to these dominant discourses that may be constraining or even annex other, more needed and healing discourses in the clinical encounter. Conrad (1992) explains, “Medicalisation consists of defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using a medical intervention to “treat it”. This is a sociocultural process that may or may not involve the medical profession, lead to medical social control or medical treatment, or be the result of intentional expansion by the medical profession” (p. 211).

This medicalisation of human experiences in illness, physical challenges and mental-emotional-spiritual struggles can constrain the healthcare practitioner’s real-time encounter with the person in front of them. Economic factors also limit the amount of time that can be spent with each client potentially coercing the practitioner to engage in behaviours that embody, despite their best efforts, efficiency over efficacy. The medicalised conversation thus tends to exclude or submerge dimensions of the patient’s unique narrative about their suffering and soul-pain (Mehl-Madrona, 2007). Antole Broyard (1992), in The Patient Examines the Doctor:

would like a doctor who is not only a talented physician but a bit of a metaphysician too. Someone who can treat body and soul. There’s a physical self who is ill and there’s a metaphysical self who is ill … To get to my body, my doctor has to get to my character. He has to go through my soul … When your soul leaves, the illness rushes in. I used to get restless when people talked about soul, but now I know better. Soul is the part of you that you summon up in emergencies (p. 40).

Broyard asserts that the therapeutic relationship often requires this submerged human person and soul-full narrative, to be engaged. As a result, practitioners are frequently ethically and morally required to skilfully allow space for these submerged discourses in order to engage therapeutically and meaningfully with their client and give them agency to describe their struggle in their own terms. These submerged discourses can include telling their story in their own way and time, and with their unique, descriptive language, grief support, story-sharing, spiritual and wisdom sharing. They engage with those aspects of personhood that throughout time have been expressed through poem, story, song, and are captured in spiritual and wisdom literature, humanities and philosophical discourses. These clinical conversations may include expressions of lament, mourning, celebration, and spirituality ideographically disclosing experiences of sacredness in living and dying.

The challenge to create space for the whole person in the client/patient’s clinical care, such that they can express their needs, tell their story and foster a healing therapeutic relationship as the site of giving and receiving medical care, is faced by clinicians of all stripes in both institutional and community-based healthcare settings. This therapeutic relationship, grounded in mindful attunement to the other, is the foundation of the essential meaning of health “care”. Without it, there is little health and, potentially, a disturbing exile of care.
Rising forces of a “politics of evidence” (Cheek, 2008, p. 278) are shaping much of the contemporary research landscape, fuelled towards an incessant economically driven pragmatism (Rossiter & Robertson, 2014). Living in these politics in front lines of healthcare, many can attest to this political force and its impact.

Carl Jung (1970) would call the social forces of the world around us “collective forces”. And they are forces. If you ever tried to speak about soul suffering, or more pragmatically dying, in a multi-disciplinary “tumour board rounds”, where nurses and allied health practitioners sit at the edge of the room and physicians sit at the centre table, discussing tumours and treatment options, you can understand forces of the collective. The ideological battle between the interior domain of the ensouled person and the medical-scientific domain, with its focus on a medicalised person whose body is a treatment site (Pauly Morgan, 1998), is extremely current and real. Yet, despite these fragmenting forces within treatment centres, patients’ encounter deeply compassionate professionals.

The Logic of Soul

Hacking (1995) asserts, “We have learned how to replace the soul with knowledge, with science” and concludes, “Hence spiritual battles are fought, not on the explicit ground of the soul, but on the terrain of memory, where we suppose that there is such a thing as knowledge to be had” (p. 6). A language of soul seems collectively lost, or at least forgotten.

What is “soul”? Not an easy notion to define. It is easier to experience than to grasp conceptually. Meanings of “soul” seem far more communicable through arts, humanities, and music than through facts. Hacking offers:

One person, one soul, may have many facets and speak with many tongues. To think of the soul is not to imply that there is one essence, one spiritual point, from which all voices issue. In my way of thinking the soul is a more modest concept than that. It stands for the strange mix of aspects of a person that may be, at some time, imaged as inner – a thought not contradicted by Wittgenstein’s dictum, that the body is the best picture of the soul. (Hacking, 1995, p. 6)

Christos’ (1976) philosophical view asserts a logic of soul, distinct from science and philosophy:

We are faced with the task of coming to terms with the fact impressing itself on us with growing urgency, that the soul has a logic of its own, an experience of its own not to be seized by languages appropriate to physical phenomena on the one hand, and to mental processes on the other. (p. 7)
Soul-Medicine’s one-on-one and group sessions with people facing their own mortality through cancer include an archaeological endeavour into the interior realms of the psyche to retrieve an ancient memory felt in our bones (Woodman, 2001). Suffering has dimensions of soul suffering that nothing less than a Soul-Medicine will assuage. In our cancer centre, what constitutes Soul-Medicine has been the focus of inquiry, person by person, in their daily life and in our sessions, as well as in the groups. While Western culture has deeply bound and conditioned medieval religious meanings to the word “soul” (De Pablo & Evans, 1994; Yoshikawa, 2009), with the meaning that Hacking ascribes, it is that aspect of our human interiority that lies beyond the reaches of the cognitive sciences. For Bachelard (1969), an early twentieth century philosopher of science, soul is that dimension of human life where, as the saying goes, pictures speak a thousand words and can cut through as well as express existential-spiritual pain with remarkable precision. Deep in our psyche, suggests Bachelard (1969) in his phenomenology on imagination, dwells the language of soul, communicating in images, feelings, intuition, metaphors, dreams, wisdom from the ages, and through contemplative reverie comes the penetrating insight of the poet, artist, sage, and shaman. Poets and sages are part of every organisation and institution, often silently writing poems, creating art, and offering salient wisdom and heart-healing stories to patients and colleagues yet their work is hidden from documentation or professional discourse.

Soulful Spaces

Todres (2007) describes a “soulful-space” in the relational dimension of psychotherapy – “a spaciousness in which vulnerability is embraced” (p. 162). This type of interaction is difficult for practitioners dealing with brief, problem-focused assessments, algorithms to screen for psycho-social distress, and countless people to be seen and treated every day. Yet despite these constraints many try to carve out time for more in-depth, person-centred conversations with their clients/patients. However, all too often such efforts seem futile with economic drivers and benchmarking determining how clinicians deliver their care. A particular kind of healthcare despair can creep into the heart and soul of the most caring clinician, eroding hope in change. Is it possible that a “poetic resistance” is called for globally to preserve the care in the delivery of “heathcare”?

SOUL-MEDICINE AS “POETIC RESISTANCE”

Poetic resistance is certainly Soul-Medicine’s discreet aim in the medical context. Kinsella’s (2006) article was perhaps prophetic towards how the arts, humanities, and health sciences, through visionary individuals, are “trying to find their way back into an interdisciplinary relationship” (p. 162). She has voiced a quest, emerging in many health-science disciplines and training programs, for a poetics of wholeness and soul-filled human experience to find their way into the discourses of science. Kinsella’s work on
rediscovering and reintegrating phronesis (practical wisdom), which arose from her own clinical practice, proposes a fluid movement between clinical practice wisdom, health education, and research domains (Kinsella & Pitman, 2012).

The central question at the heart of Soul-Medicine’s group inquiry is articulated by Freeman (1998b): “Insofar as the modern historicised self has effectively become severed from the mythical domain, the narrative fabric of the self has become frayed … an important task for thinking in modernity is to begin to imagine how the narrative fabric of the self may be knit back together” (p. 48). The biomedical discourses, even when clinicians deliver them with deep compassion, offer little to “knit the self back together”. Something far broader and more poetic, with distilled living wisdom is often needed. Despite all the gains of biomedical technology, the struggling pass through my office door. They are responding, I believe, to a “mytho-poieic desire” (Freeman, 1998b, p. 45) that thirsts for poiesis (creating) the poieic and mythical-archetypal, to overcome a feeling of fragmentation by the cognitive-rational knowledge(s) of cancer including the repetitive screenings for depression and anxiety reinforcing the “psy” (Rimke, 2010) sciences overwriting of soul language for distress (Hacking, 1995). The ‘dark night of the soul” (May, 2005; Starr, 2003) — St John of the Cross’ powerful term — requires nothing short of Freeman’s call to meet the mytho-poieic self poetically and meaningfully.

Poetics of Experience

Mair (1989) describes “the poetics of experience” in psychotherapy and worries about its disappearance:

If we destroy the whole world of experiencing, destroy the infrastructure on which they can grow and achieve recognition, then they will not exist. Needs can disappear. We can come not to need or to recognise what could otherwise have been. We could become devoid of poetic passion. We could become carefully groomed constructions of factory-made components, not voice in pain. (p. 247)

The clinical interventions of Soul-Medicine are essentially such a poetics of experience. They take place within a therapeutic clinical relationship, grounded in psychotherapy and spiritual care training, as well as within a clinical service that makes soul-care visible in healthcare. The poetics arise through Mair’s (1989) “conversational space”. The medicines are multi-dimensional and encompass a double-meaning of Western notions and indigenous meaning(s), learned from First Nations friends and elders. They have taught me that all living relations, the whole earth we belong to, are “medicines” for the whole person, without dualism of “body” and “spirit”. Soul-Medicine is a linguistic reintegration of this wisdom of the first peoples, which colonialists tore asunder and then repressed.
Soul "Medicines"

Medicines of Soul-Medicine include therapeutic presence (Chochinov et al., 2013), compassion, poetry, art, collaging, dreams, music, and giving space to explore personal expressions of the soul’s symbolic language of suffering and hope. Soul-Medicine supports, guides, and offers ingredients of soul from diverse wisdom traditions and their practices, as well as the images, dreams, and narrative inherent in the living conversation. This cornucopia assists people living with cancer in seeking a sense of integration and wholeness. It renders an invisible realm visible, as Mair (1989) suggests:

Our places of human habitation are mostly invisible. We will have to conjure out of invisibility the worlds that we inhabit. To do this we need a poetic imagination to speak of our experiencing within the ongoing conversation of our lives. To speak of what we know and do not know takes artistry, the startling uncertainty of new ways. The familiar narrative forms of ‘behavioural science’ will not do. (p. 258)

Soul-Medicine is such a conjuring of a world out of invisibility. It is made visible by asserting clinical space, discourse in medical charts, rounds and consultations, and professional conferences. Such “soul treatment” strives to give voice to the personal, the interconnected, the relational, the feeling, the intuitive, the story, and the poetic that feed poiesis, creative living, and strength in suffering. Such a poiesis cannot be reduced to its parts to be studied or treated without losing something deeply important for the assuaging of grief and lament (Freeman, 1998a, 1998b). Soul language conserves explorations of despair and hope as part of the human experience of struggle-in-life. Poetry, story, meditation, art, music, silence, laughter, exploring metaphors and images used to describe interior experiences are all potential medicines for the soul. This clinical domain of Soul-Medicine and its discourses are my own version of poetic resistance to the fragmenting, dignity-eroding (Chochinov, 2007) aspect of our medical context. To be clear, I do not suggest that soul language should replace other clinical discourses. I propose merely for the release of such a discourse and its potential, illuminated by patients’ narratives, from a Berlin Wall type annexing in medicine with its own iron curtain separating the soulful realm from integration with medical treatment. There is no clinic to treat the soul.

Soul-Medicine is thus the co-creation of many individuals in a daily, dyadic inquiry into the existential wilderness of cancer for both patients and clinicians. Many of my colleagues and other clinicians have engaged in soul-full practice, engendering living wisdom and healing interventions. Soul-Medicine, through its poetic, resistive actions, seeks to offer “treatment” for the “soul that is lesioned” (Hacking, 1995, p. 5).

Communitas and Conspiratio

In Ellis’ (2002) words, “Good autoethnography works towards a communitas, where we might speak together of our experiences, and commonality of spirit, companionship in our sorrow, balm for our wounds, and solace in reaching out to those in need as
well” (p. 41). May this story, my story, provide some soul-food to you for sustaining your own poetic-self in poetic-resistive acts, interventions, and discourses in your own life.

May it also be an invitation to trust the pathless-path and foster in your own work-life Ivan Illich’s notion of conspiratio – the conspiracy of friendship (Taggart, 2011), which Dr. Kinsella told me about in an email as we reflected on the connections between Soul-Medicine and her call for poetic resistance. It is conspiratio in hallway and coffee line conversations incepting creative alliances that have evolved Soul-Medicine, one relationship at a time. Conspiratio speaks to the power of such intangible relational forces that can perhaps offer some hope for the soulful and soul-seeking practitioners in healthcare.

AFTERWORD …

Soul-Medicine’s story comes to rest
for now
we are but movement and story… story-ing our lives
within nature’s story-ing us
stories… lives
endlessly birthing
dying
in a world where spring follows winter.

For John Graham Butlin, 1930–2014

NOTE

1 Personal conversation with Dr Carla Garcia, psychiatrist in the London Regional Cancer Program and faculty member, Western University, Schulich School of Medicine and Dentistry.

REFERENCES


BUTLIN


Helen Butlin
Doctoral Candidate, University of Western Ontario
Registered Psychotherapist (C.R.P.O) & Specialist in Spiritual Care (C.A.S.C.)
London Regional Cancer Program, London Health Sciences Centre
London, Ontario, Canada
ANGIE TITCHEN AND DIANE TASKER

21. CRITICAL COMPANIONSHIP
Nurturing Mindful Dialogues in the Midst of Practice

OPENING SPACE

Meet Katherine, an experienced physiotherapist working in a community service in Australia. This chapter is her story. Increasing complexity of healthcare and consumer knowledge, combined with overwhelming accountability measures for healthcare administrators and practitioners, inequitable access and cracks in and fragmentation of healthcare services, produces a very mixed picture for healthcare consumers. Katherine knows that, within this complexity, it is always relationships that make the difference for vulnerable, unwell people.

In creating such relationships with clients, she has been influenced primarily by the frameworks of skilled companionship (Titchen, 2001a) and person-centred practice (McCormack & McCance, 2010). Moreover, when helping less experienced colleagues to become skilled companions, she has found that many of them find it difficult to talk about, and thus critique and improve, the relational aspects of their care. Like many skilled practices, these aspects are often deeply embodied and embedded in practice and are thus inaccessible to mindful dialogue. Critical companionship, a learning relationship with colleagues, has, however, a proven track record of helping people to access and articulate embodied, embedded know-how (Titchen 2004; Titchen & McGinley, 2003; Hardy, Titchen, Manley, & McCormack, 2009).

In this chapter, we are using a “faction” genre which is fiction based on “fact”, derived from empirical research and experience. We can imaginatively show you Katherine’s inner thoughts and feelings, as she goes about her work, seeing what she notices and how she responds as she creates spaces for mindful dialogues with a client and an inexperienced colleague. The chapter is written as a mandala (see left) which shows the parts (i.e., domains which hold the processes and strategies of critical companionship) and the connected whole (i.e., unique blending and melding of the domains by professional artistry according to the particular person, needs, situation and context). The connected whole is linked with helping people to flourish.

PREPARING THE GROUND

Critical companionship is a person-centred helping relationship between a practitioner with highly developed facilitation skills, who develops trusting
relationships with and accompanies, colleagues on experiential learning journeys. Through using the whole of her/his self, the companion helps people to experience practice-based learning as inquiry in and on practice, either in the midst of everyday work or through learning supervision/partnerships, active learning groups, work-based learning, workshops or collaborative inquiries. The companion enables people to develop new knowledge and ways of knowing, blend these new insights through professional artistry into practical know-how and then using this know-how to transform themselves (if they so wish) and their practice.

Through her reading, Katherine discovered that critical companionship was developed by Angie in her PhD research and throughout her career as a practice developer, facilitator and action-oriented researcher (Titchen, 2000; 2004; Hardy et al., 2009; Titchen & Peelo-Kilroe, 2014). As she read of people’s experiences of using the critical companionship framework (e.g. Gribben & Cochrane, 2006; Titchen & McGinley, 2003; Greggans & Conlon, 2009; Brown & Scott, 2010; Eldridge, 2011), she began to appreciate the complexity of enabling person-centred helping relationships and creative spaces. She learned that practitioners could find their own personal meaning by relating the framework to their own practice, as they are reading it. Then, they could try out bits of it (one chunk of the elephant at a time), notice and evaluate what happened before going back to read it again.

There are four domains in the critical companionship framework with one overarching domain (Figure 21.1), each with a number of specific processes and strategies. All of the domains except the facilitation domain are also found in the skilled companionship framework, although they are likely to be delivered differently in the context of the practitioner/client relationship. In the following faction, the domains, processes and strategies used by Katherine are shown in italics. The spiralling river in the figure symbolises the energy of the relational space created by the companion’s professional artistry in the turbulence of practice.

The relationship domain has four processes: mutuality (working with, in partnership); reciprocity (reciprocal giving and receiving of wisdom, care, concern); particularity (getting to know the particulars of the other as a whole person in his/her situation and contexts) and; graceful care (authentically engaging the other as a whole person with the whole of oneself and being kind/present/emotionally engaged but balanced).

The blended rationality-intuitive domain has three processes: intentionality (being deliberate, purposeful cognitively and intuitively); saliency (knowing what matters/what is significant/what needs to be paid attention to); temporality (past, present future time, timing, timeliness, pacing and anticipating).

The facilitation domain has four processes: consciousness-raising (enabling conscious awareness of taken-for-granted assumptions, embodied wisdom and the carrying of culture in the body, discourse and language); problematisation (helping others to see problems that they are not aware of; or, re-framing problems to help others see things from different perspectives); self-reflection (helping people to reflect on themselves and their practices to develop self-knowledge and to be able to evaluate their impact with others); critique (engaging in critical-creative
dialogue with self and others to co-create and contest new knowledge and understanding).

The overarching domain transformational use of self is enabled by professional artistry (Titchen, 2009). Professional artistry is the means through which the critical companion blends, “dances” or improvises any combination of the domains, processes and their strategies to meet the particular needs of people being helped in relation to their particular experiences, contexts and situations. Thus critical companionship is not a “one size fits all” approach!

![Critical Companionship Diagram](image)

Figure 21.1. Key components of the critical companionship (CC) & skilled companionship (SC) frameworks (the full frameworks are published elsewhere (Titchen, 2001a; 2001b; 2004; 2009; Titchen & McGinley, 2003)

There are seven professional artistry dimensions: artistic qualities, such as connoisseurship, disposition to what is good and audacity, different knowledges (local, practical know-how, personal and propositional knowledges), different ways of knowing (pre-cognitive, cognitive, metacognitive and reflexive), multiple intelligences or wisdom/capacity to grasp something quickly and enable the use of multiple knowledges etc. in the moment (embodied, aesthetic, emotional and spiritual intelligences), multiple discourses, creative imagination and expression and artistic and cognitive critique. Often hidden beneath these more visible dimensions are the professional artistry processes: attunement, interaction, synthesis (blending/melding), balance, flowing, energy and synchronicity.

**GETTING TO KNOW GLEN AND PLANNING TOGETHER**

While driving between client visits on a quiet country road, Katherine reflects on her interaction with a young colleague, Glen. It became clear to her yesterday, at their regular practice meeting, that Glen is now wanting and needing to talk more about the way he practises his physiotherapy, especially the intricacies of the human interactions that he comes across in his practice. She knew this was a significant issue to attend to (saliency – rationality-intuitive domain) because she
had noticed that Glen often introduces such concern by means of a story from his practice. Like yesterday, he said, “I went to see Mr Smith, the fellow with the left-sided stroke you referred to me. He’s very happy to do a few exercises or chat, but I’d love to get him outside into the garden and walking again. I don’t think he’s been outside for months.” Whenever I bring up the idea, he says, “That would mean I would have to get dressed”. I don’t think I’m doing any good there. Glen looked at Katherine, obviously hoping that she might be able to offer a “quick fix” to this frustrating situation. She smiled with him because she knows that feeling too.

I told him that being experienced doesn’t mean that I can just walk into a situation and “make it work”. I have to do my ground work relationally too; getting to know the other person, finding out what is important to him, sharing where I am coming from and waiting until we are both comfortable before attempting to extend any activity together (articulating her craft knowledge, a strategy in the facilitation domain) of particularity, a process in the relationship domain). To problematise (a process in the facilitation domain) his assumed way of being with and relating to clients, I asked him, at that point, what he knew about Mr Smith and his family (intentionality, a process in the rationality-intuitive domain). Glen was unable to move beyond the clinical aspects of his case. Later, when he talked about finding a clinical supervisor in the community, I thought that maybe we could intentionally use the strategies of critical companionship by working together in the community. We could use powerful role-modelling combined with articulation of craft knowledge strategy and observing, listening and questioning strategy of the facilitation domain in the actual context of practice. Also, I would have to show Glen how to dig out my craft knowledge (practical know-how) that I might take for granted, as well as, my embodied and, therefore, no longer conscious knowledge. Moreover, because colleagues giving each other constructive feedback and critique does not necessarily happen everywhere, I would have to work hard to create trust between us to enable that.

At their next practice meeting, Katherine suggests that they could become critical companions to each other, inquiring into their own practice (reciprocity - relationship domain). Glen looks unsure, but when Katherine explains that she would be helping him with his inquiry into the relational side of his practice and that she would be inquiring into how to help him to learn from his own practice, his facial expression and body posture changes. Glen is keen.

Katherine knows that good beginnings to any relationship are vital, so she proposes that they need to take some time to get to know each as people (timeliness, pacing – temporality) and to find out where each of them are starting from in their understanding of how they might help each other (particularity). They arrange to go for a coffee together in a local café. When they have ordered, Katherine says, “would it be a good idea to share something we have in our pocket that says something about who we are?” They laugh together at the seeming absurdity and Glen pulls out a plectrum and says, “I play guitar in a Rock and Roll band!!” Both roar with laughter and then Glen asks “Now what’s in your pocket, Katherine?” Katherine gently pulls out a small oval pebble – smooth and white. “I
was sub-contracted last year to plug gaps in a disability organisation to provide professional support to community physios in giving care to families. When I left, one of the physios gave me this stone. She said its elegance and simplicity symbolised the kind of support I had given her. I keep it with me always, to remind me of the power of working with the whole of ourselves.” “Blimey”, says Glen.

After a while, they agree to work out together (mutuality – relationship domain) the purpose of the companionship and their respective roles and responsibilities, in much the same way one would do for clinical supervision. Katherine asks about Glen’s experience of his previous supervision and what worked well and not so well (particularity). He replies that whilst he had learned a lot from his clinical supervisor, he didn’t give him much rein and he was beginning to resent it. The supervisor was also his manager in the hospital and had assumed a hierarchical relationship between them with him as the expert (teacher) and Glen as the learner. The dialogue between them had been entirely cognitive and largely about the technical side of physiotherapy. Glen asks how critical companionship is different and she is able to contrast his experience of clinical supervision with critical companionship in terms of power and context in which it is carried out.

Katherine explains that they will be co-learners and inquirers into their own practices and will be equal partners, even though Katherine is more experienced as a physiotherapist and his contractual boss. They would act as guide and resource for each other. Glen felt slightly anxious about it, but Katherine quickly put him at ease by explaining that she too would be learning how to help someone with less experience with clients to learn in and from their own practice (graceful care – relationship domain).

Katherine helps Glen to choose his first inquiry question and suggests that he keeps it manageable and action-oriented. It ends up (for now) as, “How can I learn to do the ground work in order to help people to move out of their comfort zones and take the next steps forward towards a better quality of life?” Katherine asks if Glen would like to come and observe her working with one of her clients, Frank. “He is in a similar situation to Mr Smith and it might help you to come and observe me working with him.” “Yes, please, says Glen. “In that connection”, says Katherine, “my inquiry question is, “What is the nature of my own professional artistry as I help Glen, as his critical companion, to answer his inquiry questions through consciousness-raising, problematisation, self-reflection and critique (processes of the facilitation domain)?”

ON THE WAY TOGETHER

A few days later, Glen and Katherine go to see a client, Frank. She had phoned earlier in the week to get Frank and his wife’s permission to take Glen and explained why. They were very happy for him to come and she and Glen have discussed how they might manage the visit in a person-centred way that wouldn’t disrupt the close relationship already established with Frank and his wife. In the car, Katherine recaps what she has already told Glen about Frank - how he is an older fellow, a veteran, who spends the day in his pyjamas and hasn’t been out of
the house for months. “At the first two visits (this is the third), we established our relationship through natural conversation about his life. Every time I left, we came up together with various options for getting out (mutuality) and he promised that he would have a go, but he didn’t and still hasn’t. My plan today is to build on my observation last time that Frank sits in a chair facing out of the front window and watches everything going on, especially relating to the new neighbours. Today, I am going to be alert to that and seize any opportunity that arises.”

Glen has been doing some reading since they met in the café. “Katherine, I read in one of Angie Titchen’s publications how one skilled companion gets to know her patients”. Here is the quote:

For me, assessing a new patient is an infinitely variable interpersonal process; not a predetermined procedure. The process is adapted according to the patient’s condition and how he responds to me, and according to other demands within the ward. But in some way or other, I spend time being with the patient and, at some stage, his family too. I listen to his story, as he presents it, encouraging or empathizing in whatever way seems helpful at the time. I try to discover “where he is at” and what his perceptions and concerns are. As I listen, my nursing observational skills are at work, partly at a rational, partly intuitive level. I pick up cues that my professional knowledge enables me to recognize as significant and worthy of further exploration. As the conversation proceeds, or maybe at a later stage, I ask questions that arise from the patient’s story or from what I have observed or sensed. In this way, I begin to get to know the patient and his family and build a relationship with them. (Titchen, 2001a, p. 71)

Glen goes on, “Is this stuff about skilled companionship still relevant today and to community physio and how do you get to know your clients?” “Well”, replies Katherine thoughtfully, “To help you to answer your own question why don’t you observe me and then, on the way back, we could go for a walk on the beach and you could ask me focussed and specific questions about what was in my head, what I noticed/felt, what mattered, why I did/said what I did and so on, so you can uncover my craft knowledge, Glen … the stuff you won’t usually find in the books about creating relational spaces with clients (high challenge; role-modelling with articulation of craft knowledge). It may be that if there are any new insights and understanding arising they might help you move on with Mr Smith.” Glen agrees and suggests that he spends the last few minutes of the journey in silence to think back to how he first established his relationship with Mr Smith (self-reflection – facilitation strategy). “Good idea, Glen!” (high support). They arrive at Frank’s house. Katherine recalls in her reflective inquiry notes that she prepared when she got home that night:

I asked Frank to tell Glen about his local community and how he had come to be living there (intentionality; saliency). I commented on the beautiful roses growing in his and his neighbour’s front gardens as I knew that Frank and his neighbour had planted them together (particularity; graceful care). I did this
as a way of helping Frank to get started (intentionality; saliency) and he told Glen that he had lived in this house since he had been married. The next-door neighbours, Jim and Mary had also moved in at the same time and he told Glen about the roses and how Jim had died five years ago and Mary had moved into a nursing home. We sat quietly for a little while after this (graceful care) and I saw Glen’s face reflect his realisation of the effect this must have had on Frank (consciousness-raising). I asked Frank if he had met the new neighbours (saliency). He said, “They are a nice young couple. I’ve wondered what they have planted in their back garden, but I can’t get my wheelchair down the side path to have a look.” We talked a bit about paths and wheelchairs and how much walking he was actually doing (intentionality; re-framing the problem – problematisation). He said that he had been walking down the hallway using a forearm-support walking frame and thought that his walking had improved, but the hallway wasn’t very long. I asked him if there was a longer pathway we could practise his walking on and Frank said that the path down to the back vegetable garden was longer and level and that, perhaps he could walk there and just put a jacket on over his pyjamas (mutuality).

The weather was nice and sunny. As Frank walked with his frame along the back garden path, he stopped to show us where he used to grow his vegetables. We sat on a bench near the fence. Frank pointed out the recently built wire-netting framework for a new veggie garden next door. He said he wondered what they were planting and mischievously asked if I would help him construct a platform of bricks to step up onto, so he could see over the fence into his neighbour’s garden. I looked at Glen and we all laughed. We shared glances, Frank hopefully and Glen and I somewhat ruefully. Glen raised his eyebrows at me and I made a decision. With a handled belt and the walking frame to step onto our constructed platform (as advised by ex-builder, Frank), we assisted him to do what he wanted to do (mutuality). He then rather gleefully described in detail all the plants and building that had been done in his old friend and neighbour’s garden. Our laughter as we returned to the house afterwards expressed the fun that we had shared. I said that I wondered whether we might as well explore the possibility of helping Frank walk with his frame out to the post box on my next visit. Frank laughed again and said, “Well, if I can do this, I guess I can walk out to the post box as well”.

Sometimes physiotherapists and their clients just have to be brave together.

STARTING A MINDFUL DIALOGUE

On the way back in the car, Katherine checks with Glen, “Are you happy to start our mindful dialogue now in the car and then stop off for our walk to continue it for half an hour?” (mutuality) Glen is really happy with that. So Katherine suggests that they work with the principle they had agreed to earlier about feeding back to
her, by using the phrases, “I saw”, “I felt”, “I imagined”, so that he is offering her his interpretations and not telling her what her interpretations were. Glen says, “Well the first thing I saw was you asking Frank to tell me about his life. You didn’t seem in a hurry to get the social bits done before getting down to the “real” work of the visit. It seemed to me that you were trying to show me how being interested in a person’s life beyond the current need for physiotherapy was key. With Mr Smith, I haven’t done that, I have been overly concerned, I see now, with achieving functional outcomes, so I know very little about his past. I see that if I did, I might be able to get him to talk more easily about how the constraints to his movement are affecting him. It would also make me more alert to opportunities to help him to see that something is possible, like the walk down the back garden path helped Frank to think of creating a platform of bricks. You created the space for him to be in control of the building because you knew that he was an ex-builder!”

“So can you relate that, Glen, to the skilled companionship framework?” Glen looks blank at first, but Katherine’s silence gives him time to think. “I think it is tied in with getting to know the client through social conversation (which I have always considered to be time-wasting chit-chat!), so that you can design care that starts where they are. This is likely to be effective in achieving functional outcomes because the care suits that particular person (ah, yes, that’s why it’s called particularity!). It increases the person’s well-being.”

Katherine comes in here, “Yes, I think you are right (high support). Gentle and sensitive conversation is needed to negotiate fear or unspoken concerns. Clients in such difficult situations might need time and conversation to think through the difficulties they face if they are to be able to increase their physical abilities, but also their sense of wellbeing. We have to let go of the urgency we feel when focusing on our professional accountability for functional outcomes. What do you think, Glen? Glen nods his head several times in agreement. “I’m feeling guilty now for putting my own needs as a therapist in front of those of my client (self-reflection; critique).” Katherine says, “Letting go of that urgency is part of every physio’s journey as they move from being a novice towards expertise. Your insight into yourself and having the courage to share that with me is a huge step forward (giving feedback). It shows me that my attempt at problematisation (helping you to see something unproblematic) to you, is a problem and then re-framing your guilt as evidence of growth”.

Glen looked a bit relieved and went on, “Another thing I noticed was that you used silence a lot in the conversation. It gave Frank time to tell me about the enormous effect on him of losing his neighbours and his own mobility as well. I always try to fill that kind of silence, so I have probably been missing important things that really matter to my clients. And by the way, I have just experienced the positive effect on my thinking of you being silent with me just now! You also involved Frank in all the decision making; that was so cool, and that, Katherine, was an example of mutuality – it was a real partnership!” Glen looked pleased with himself for having recognised a process from the skilled companionship relationship domain! He went on, “However, there was one brief moment where I imagined you were making a professional decision about his and our safety. It was
after you gave me that look, when Frank asked us to help him build the platform! In a split second, you made the decision to take a calculated risk and it worked!! Now that, I imagine, is expertise in clinical reasoning, Katherine. I don’t know what part of skilled companionship that is. Maybe it is something to do with professional artistry – that multiple intelligences stuff?"

FROM COGNITIVE TO EMBODIED, CREATIVE DIALOGUE AND BACK AGAIN

Arriving at the beach, Katherine suggests that, rather than continue with the cognitive analysis of what Glen has observed, they use getting out of the car as a transition point from cognitive dialogue to embodied, creative dialogue without words. “When we get out, we could take a few deep breaths and then start walking together, in a kind of contemplative way, in tune with each other, but not necessarily close to each other. I invite you to open up your body senses and just notice what you notice. If it is appropriate, actually pick it up. There is no need for there to be any reason. When we feel ready to come together, we can indicate that to each other, without words, and then create something together, using what we have collected or anything else to hand. We may want to do it separately. We could then share and talk about our creations and find out if they tell us something else about what happened today with Frank. A very important thing to remember about this way of working is that we are just using another way of expressing ourselves, not creating a piece of art.” Glen says, “OK, Katherine, I trust you and I am prepared to take the risk to do something I have never done before. I imagine that Frank felt something like that today” And so they set off, the wind in their lungs and ripping at their bodies.

After 15 minutes of reflection, they come together and start, spontaneously and silently, to create – Katherine a mandala with smooth, white stones and Glen wind music with shells tied to a bit of driftwood with string. When they indicate to each other their readiness to engage in a cognitive and artistic critique (a dimension of professional artistry), Katherine begins ... “I have created this stone circle to honour our new critical companionship. It holds the parts of critical companionship together as whole. The gaps between the stones show the flow of energy we have created today. In the centre, I have placed a starfish to represent a new question in my inquiry, i.e., ‘Is the facilitation domain of critical companionship also relevant to skilled companionship?’ Today, I think I could see us using the consciousness-raising and problematisation process with Frank.” Silence.

Glen begins to share his creation. He seems very moved, “My wind chime reflects the grace and fluency inherent in your work today with Frank and with me.” A gust of wind, rings the shells, “This wind music sends a message of skilled and critical companionship! Silence. This is a huge insight for me today and I know that it will take me some years to develop this ‘music’ in my work. This painful learning that I do not intentionally get to know my clients as a whole person, has inspired me to develop the relational side of my care. I am going to talk to Mr Smith tomorrow and try to get to know him more.”
NOTE

1 Katherine and all other characters in this story are composites of us and people we have worked with in our practice and research.

REFERENCES


Angie Titchen DPhil (Oxon), MSc, MCSP
Visiting Professor, University of Ulster, Northern Ireland

Diane Tasker PhD
Education, Practice and Employability Network, Australia
JOY HIGGS AND DIANE TASKER

22. PURSUING PRACTICE MINDFULNESS 
AND WISDOM

The sub title of this book, “The search for mindful dialogues” forms the focus of this chapter. The main title, “Community-based healthcare”, gives the context through which we have examined the concept and practice reality of mindful dialogues. In this chapter we are linking the research Diane conducted on mindful dialogues with other research Joy has been leading for some time with Diane and several others, about practice wisdom. (Block quotes in italics below, are derived from the latter research program to add to the many quotes in the book from Diane’s mindfulness thesis.)

Words like mindfulness and wisdom with their connotations of gentleness and obscure or ephemeral ways of thinking and acting are often discarded or rejected in this age of science-driven evidence for practice and accountability, and in a world where chaos-fluidity and technological communication rule supreme. We hear people talking disparagingly of being “thinky-feely”, using “old wives’ tales” and (ultimately) being unscientific, to describe actions like mindfulness and practice wisdom. These denigrations demonstrate lack of recognition of the substantive discourse on the nature and value of practice wisdom and experienced-based knowledge (see Küppers & Pauleen, 2013; Sternberg, 1990) and the genuine purposes and actions underpinning mindful people-centred practices (see Mansell & Beadle-Brown, 2004; McCormack et al., 2010). A number of writers have drawn these two ideas together. Boyle and Roan (2013) explored “wise women or caring women: The paradoxical nature of the representation of women in management” and Mearns and Thorne (2000) discussed new frontiers in theory and practice of person-centred therapy, considering deeper issues of such practice in terms of personal commitment and professional credibility.

In society, beyond professional practice, a surprising phenomenon is emerging, perhaps in the search for humanity and purpose and for a way of spiritual being that is beyond formal religion and orthodoxy. People are seeking something more to make sense of a time of political upheaval, unbelievable human displacement and natural world chaos. We see, for example, spontaneous crowd choirs bringing surprise and delight to the general populace, countries welcoming massed refugees and people taking time to share insights across social media. These happenings are mindfulness in action and they demonstrate personal humanity and a recognition of wisdom, of the need for spaces of calmness and belief in helping others that is not because of regulation or personal gain. Such actions and occurrences exist in the deeper spaces of being that belie the surface floating of commercialism, celebrity, short-gain entertainment, self-gratification and personal ambition that are widely
evident today. Rather they delve below the surface to access meaning as a way of energising life efforts.

A PLAN FOR PURSUIT OF MINDFULNESS AND WISDOM

Mindfulness and wisdom can be thought of as phenomena (things and happenings, that can be understood abstractly and experienced in life), as aspirations to be pursued, as lived experiences and, particularly, within professional life, as practices. All of these interpretations and manifestations are encompassed in the idea of practice as having four key dimensions: doing, knowing, being and becoming (Higgs & Titchen, 2001a,b). To understand practices deeply, to perform them, to embody, live and experience them and to become “better and better” at all of these things, requires appreciation and realisation. Appreciation involves firstly, valuing practices – for why else would you set out to pursue them, secondly, having an understanding and deep awareness of what they mean, of their nuanced and situated nature and how to enact and live these practices, and thirdly, it involves the capacity to critically appraise them, for instance, as a connoisseur appreciates fine art. Realisation, similarly involves valuing and understanding and adds the capability to make practice happen, to realise it by bringing it to reality (Higgs, 2012).

PURSUING KNOWING ABOUT AND WITHIN MINDFUL AND WISE PRACTICE

While the topic of wisdom in general has long been of interest to scholars, its existence and development within the world of professional practice has been less developed, being complex and often subtle in its expression and undervalued in the modern world of empirico-analytical practice drivers and frameworks. Exploration of the nature of practice wisdom and mindful practice could lead to a better understanding of how it might be encouraged for all practitioners.

Wisdom is knowing in a way that involves insight, discernment of right and wrong, and the capacity to choose between options with sound judgement and sagacity or foresight. (Higgs, 2012, p. 75)

Boyle and Roan (2013 p. 102) take us back to Aristotle’s original definition of wisdom which is to act “with regard to human good” in a manner that is applied in “a reasoned and true state of capacity within both broad and situated contexts” (Aristotle, 1998). Aristotle proposed three kinds of knowledge associated with wisdom: epistêmê (necessary, universal knowledge), tékhnê (knowledge of procedure, technical knowledge) and phrônêsis (practical wisdom). Exploring these knowledges Higgs (2012) presents a tableau of ways of realising practical wisdom (outcomes and building blocks for practice, knowledge and further wisdom) from the pursuit of wise practice (deliberate process).
Practice wisdom is born (from practice) of multiple ways of knowing through experiences, learning, reflecting, critical dialogue, making theories, and creating and testing hypotheses. (Higgs, 2012, p. 75)

Practice wisdom combines many different facets of practice in complex presentations but the combination of its different facets makes it very recognisable to other people. From our research on practice wisdom we have ascertained identifiable qualities of wise practitioners to include: using insight and discernment, seeking and valuing different ways of knowing, valuing emotional intelligence, embedding reflection and reflexivity within practice, imbuing practice with ethical courage and values and embracing a wholistic perspective.

To know about mindfulness is to understand it as a way of being and of experiencing that being in a heightened senses manner, and a way of knowing and being aware of things and people and happenings around us. It is also a way of doing and interacting with others that is mindful and considerate of others’ perspectives and needs as well as our own. Further, it is a way of growing in these things – also mindfully, critically and aspirationally – to become more mindful.

Knowing mindfully and wisely also encompasses learning about and critically appraising our practice knowledge – its functionality, adequacy and credibility. A key aspect of becoming a professional is accepting and pursuing the responsibility to contribute to the knowledge base of one’s profession and to build plus continually refine one’s own knowledge base and professional practice model. This involves having a rich understanding of the content, credibility and limitations of these knowledge bases – both at the core and margins of professional practice discourse and lived practice (Higgs, 2016). Alongside this knowledge building, professional socialisation is a space and journey where novice professionals learn what it means to be a member of their profession including the knowledge base, language, behavioural norms and cultural practices (Higgs, Vann, Tasker, & Chambers, 2016). They also learn to reason in ways consistent with their profession and their own practice models (Ajjawi and Higgs, 2008).

Building on this knowledge of mindfulness and practice wisdom is knowing-in-practice. This includes using knowledge of life and one’s practice field (using all three of Aristotle’s kinds of knowledge), using cognition (particularly professional reasoning and decision making) and metacognition (of thinking about what you’re thinking about). Interestingly, metacognition could be conceptualised as being mindful about one’s own thinking, monitoring and being prepared to adapt this knowing-in-action to the current situation and events of practice.

As well as using metacognition and mindfulness during knowing-in-practice, wise and mindful practitioners would bring what Watson (2001) calls intentionality and caring-healing consciousness into the planning of practice. Such intention includes planning goals and strategies which is essential to the implementation and pursuit of practice wisdom and mindfulness.

Intentions remind us of what is important … intention informs our choices and our actions … our intentions serve as blueprints, allowing us to give
shape and direction to our efforts and our lives …” (Kabat-Zinn, as quoted by Watson, 2001, p. 12).

PURSUING DOING: ENACTING MINDFULNESS AND WISE PRACTICE

Wisdom is not just a way of thinking about things; it is a way of doing things. If people wish to be wise, they have to act wisely, not just think wisely. We all can do this. Whether we do is our choice. (italics added) (Sternberg, 2003, p. 188)

Mindful, wise practice is more than just simple intention to carry out planned action. Rather it involves grounding of informed intent to meet the expectations of the practitioners’ own practice model, to fulfil their professional reasons for practising, and to uphold their basic ethical responsibility in contracting with clients to provide a quality and genuine service that has an outcome beneficial to that client.

Practice wisdom has more of an intention around it; (it means that) you’re actually organising the way in which you’re going about things.

You absolutely need to understand the strategic intent of where you're going but with an eye on the client. Then I think you never lose sight of what it is that you need to do and how you need to do something.

Beyond intention and implementation of mindfulness and wise practice, we have reason to expect our wise practitioners to be able to articulate their reasoning, strategies and critique of practice. To bring credibility to practice in an age of accountability and evidence-based practice we cannot keep its rationale hidden. To elevate practice wisdom to “sound practice” also requires clarity and credibility through articulation. Further, articulation is essential in shared client care situations (which are, indeed, more the norm than the rare).

Wisdom, I believe, is being able to articulate where you’ve drawn it from. So, it has a certain intention about it, inasmuch as you’ve come to be able to apply and discuss and share the practice, what the roots of that practice are, where you’ve, how you’ve gained that practice - whether you’ve gained it through reading, through theory, through observation, through instruction that someone else has given you, through comparing the way you do something with the way that someone else does it, through professional evaluation that you’ve maybe benefited from a supervisor or from a colleague.

Professionals should be capable of making sound decisions and taking actions that are relevant to the context of their clients’ needs and interests and within the scope of the practitioners’ abilities and practice models. Wise, mindful practitioners achieve these goals to the highest levels of performance, grounded in humanity, rich practice knowledge and a depth of practice experience that transcends textbook situations, simple client contexts and the use of commonly shared
professional knowledge (Higgs & Gates, 2013, p. 50). How can practitioners manage the integration and balance of such complex processes? We argue that it is through “practice wisdom” that balance between knowledge, power, technical practice and ethical concern can be achieved.

The relational nature of practice wisdom emerges through the development of extensive knowledge, deep understanding and professional and life experience. Wise practice is not merely generated by the application of technical expertise. A broader integration of knowledge, understanding and experience applied in a systematic and consistent manner is required to achieve desired goals or outcomes for clients, their families, community and eventually society. This requires much iterative effort and revisiting of issues especially when a practitioner is not at first able to solve a complex issue in practice. Uncertainty presents itself at many stages of decision making for practitioners.

Practising in conditions of uncertainty is an important requirement for practitioners, given that the professional practice often requires constant testing and modification “in context” to determine the next decision to be made in ongoing practice.

*I think actually, practice wisdom is recognising that you don’t always know and that you can’t always know and that it’s not certain and that sometimes you have to make a decision that appears certain but on a bit of uncertainty, but also not to lock down on that and pretend it’s a certain decision. To realise that you might always need to come back to it.*

PURSUING BEING: EMBODIMENT, OWNING PRACTICE AND MORAL COURAGE

Looking at people and phenomena as nouns (things) and verbs (evolutionary processes) (Fuller, 1970), we contend, is a valuable way of exploring their nature, depth and nuances. Higgs and Horsfall (2007, p. 239) make this useful distinction: “nouns are abstractions, symbols prompting vision, representing things that are widely accepted; (nouns) are more general, passive and distant, more finished”. By comparison, “verbs are active immediate, particularised and person-based - they represent experiencing and understanding of being in the midst of the lived experience”. In our two projects we have explored the differences between mindfulness and being mindful, and practice wisdom and practising wisely.

Consider the verbs – being mindful and being wise in practice or practising mindfully and wisely. Both ideas are expressed in the present tense – we are *being* them and they are ways of *being*. Being mindful in the model arising from Diane’s doctoral research (see Chapter 5) was described as follows. Central to a mindful approach to therapist-client relationships is an embodied awareness of the particular context, experience and wishes of clients, families and carers across all aspects of community-based healthcare practice. Being mindful involves blending together, understanding (mindfulness) and (mindful) actions that embody practitioners’ understanding of the patient’s (and family’s/carers’) narratives and situation. Various dimensions of being mindful identified in this study were:
understanding the nature of the practice world, being sensitive to clients’ needs and challenges, recognising the impact of practice interactions on clients’ lives, realising that client-practitioner relationships need to evolve, adapting to clients’ situations, bringing personal and practice selves into interactions with clients, being open to emotions and meaning pursuit, and perceiving themselves as fellow travellers, on a journey with the people they are interacting with.

Dealing with the essential complexities, inconsistencies and uncertainties of practice requires practitioners to have strong qualities of persistence and courage if they are to work in their clients’ best interests and wellbeing. Ethical courage is needed in many different spheres of practice, for clients, colleagues, self, community, and society.

It’s ethical courage because it’s this courage to do the right thing or what you believe to be the right thing for the best outcome for that person.

Sekerka and Bagozzi (2007 p. 135) recognised the importance of intention in what they called moral courage, defining it as “the ability to use inner principles to do what is good for others, regardless of threat to self, as a matter of practice” and involving “the conscious reflection on one’s desires to act, or the lack of such a desire thereof, as one moves towards engagement to achieve a balance between personal standards and desires”. This tension would seem to be inherent in professional practice, placed as it is within society where its practitioners need to intervene in the interpersonal and personal affairs of people. Putnam (2003) also spoke of a “courageous ethical reflex” but noted “you need to be prepared in your mind and character and be ready for a response” (para 6).

I think that is where you blur that line between being a wise practitioner and practice wisdom. To develop practice wisdom in uncertain situations, you’ve got to have that courage to step up and try something different. And that’s always when it is hardest to do it.

Mindfulness and wisdom may, as terms, focus much attention on the mind. However, practice to be mindful and wise also needs to remove any split between the body and the mind. Green and Hopwood (2015) present professional practice as being embodied, performed in specific space-time by material and corporeal beings. They contend that we (educators, practitioners, researchers) need to reconstitute the notion of the professional subject and question the dualisms often apparent in learning, practice and the literature, between mind and body, between self and other, between human and non-human, between space and time and between flesh and image. Mindfulness, then, and particularly being mindful, in practice really cannot manifest itself outside of our embodied actions and ways of being with others. And, wise practice is, at its best, something that is happening and being in practice not about it. Our corporal beings provide the means and grace to fulfil our wisdom. When we are being the verbs – we are corporeal, sentient, agential and feeling beings.
Practice wisdom is an aspiration as well as an ongoing process since it occurs within and about a phenomenon, professional practice, which is inherently social, complex, relative and situated. Schatzki’s (2002, p. 71) theory, defined practice to be a bundle of activities, “an organized nexus of actions”. Higgs (2014, p. 260) further proposed that advanced practice can be seen as building upon a platform of capability and understanding that is refined through challenges and reflexivity leading to reshaping, deletions and the addition “of nuances and finesse as well as those human understandings that emerge from genuine and respectful human engagement”.

_For me practice wisdom is doing something in an applied way with the benefit of the knowledge and experience that you have accrued and are accruing over time, and it’s continual and continuous improvement and renewal process. It has at its base, an intention to know why you’re doing something, what you’re doing, how you’re doing it and how you could improve upon that._

Knowledge is created for and arises through experience of practice. So too wisdom can arise from practice that is engaged in mindfully and reflexively. Being wisely, mindfully intentional in one’s practice, reciprocally presents an essential part of becoming wise(r) in practice. People seeking wisdom may be sensitised to the gaining of wisdom through observation of and interaction with wise practitioners.

_It’s something young people strive for. They want to be good at what they do. They want to know what to do in whatever field they’re in and that’s what practice wisdom is about. It’s more of a goal for people and a sensitising concept, if you like – something for them to look for in themselves and in their colleagues._

From the other side of the interaction, wise practitioners inevitably become connected to the people around them seeking wisdom through mentoring. This promotes self-critique and evolution, increasing their own wisdom through these interactions. Thus mentoring can become a dialogical process developing over a lifetime of professional practice. Professions can benefit from such continuous improvement and ongoing renewal, which enables the platforming of wisdom for novice and experienced practitioners.

The lens of temporality emerges throughout our practice journeys, assisting us to better understand practice wisdom and what it can mean being wise in practice. Practitioners speak of an evolving and continuing journey iterated by processes of reflection and reflexivity and driven by practitioners’ motivation to learn and improve their practice.

Practice wisdom can be gained through an individual’s practice over time. This can be facilitated by dialogical processes which help to integrate their knowledge, experience and relationships by:
- enhancing interpersonal connections (which involves observing and listening to people, relating, negotiating and communicating well, sharing knowledge)
- embedding reflection and reflexivity within professional practice (which involves knowing deeply, being aware of roles in the relationship, making mistakes and learning through practice, learning and building one’s capacity, changing oneself and one’s actions to the circumstances, and being prepared, to operate outside the norm)
- imbuing professional practice with ethical values (which involves understanding and valuing ethical and moral practices, being able to see the situation from others’ perspectives, being conscious of the implications of one’s practice, applying wisdom and doing good)
- embracing a holistic view of practice that moves beyond the particular and the momentary (including understanding the bigger picture, sharing leadership and decision making, changing perspectives and actions as needed, and being prepared to challenge and move beyond the expected).

Practitioners in our practice wisdom research, perceived that the process of seeking practice wisdom tended to overtake its achievement and recognition. As individuals achieve practice wisdom (as recognised by their peers and others), they often no longer need that recognition but pursued knowledge and wisdom for its own sake, growing beyond their boundaries and seeking then to mentor others to transfer knowledge, attempting to “give back” and “do good” for others, their profession and their community by joining them on the journey.

Wise practitioners seem to take you, they seem to join you on the journey rather than give you the solution from the outset.

In such an iterative process, practitioners who become wise, can again become aspirants to further practice wisdom in an ongoing and emergent manner. This humbling process perhaps mirrors the human condition itself through its realisation of the impermanence of human endeavour and achievement. Only by passing on knowledge to the new generation can the evolution of that knowledge be ensured.

CONCLUSION

Becoming progressively wiser and more mindful is a combination of doing, knowing, being and becoming; this is the practice of pursuing practice wisdom. This journey of seeking practice wisdom and mindfulness comes full circle when an aspirant to such practice, having journeyed towards its achievement through difficult and iterative processes of reflexion and reflexivity, reaches a place where they no longer feel the need to achieve recognition of wisdom and mindfulness for their own sake. Rather they seek to share and mentor colleagues and novices through the wisdom they have already achieved. Paradoxically, such dialogical processes of sharing and mentoring can help them to continue to grow their wisdom and that of the people they mentor in an ongoing process of renewal.
REFERENCES


*Joy Higgs AM PFHEA PhD  
Director, Education, Practice and Employability Network, Australia*

*Diane Tasker PhD  
Education, Practice and Employability Network, Australia*
23. A FINAL WORD

Reading through the chapters of this book is a humbling experience. For health professionals, who have been trained/educated, and have practised in the world of acute care, it is a revelation to discover some of the complexity that characterises long-term care in the community. A number of recurring themes keep making an appearance in many of the chapters. In this final chapter we shall try to summarise some of these themes and discuss their implications.

RELATIONSHIPS

If there is any one theme that can be used as an overarching idea then it is probably the importance of relationships. There are the obvious relationships between clients and health professionals but then there are the other relationships, between clients, health professionals and other carers, including family members. There are also relationships between various health professionals, such as doctors, case managers, physiotherapists and others. These people, in turn, have relationships with the systems and organisations that employ them (or reimburse them) and that have a say in resource allocation.

It is clear that there is a great deal of complexity involved in these interactions, and health professionals who take on work in long-term community-based healthcare have to navigate this complexity and master all the nuances and subtleties of the relationships involved. The contributors to this book may not have previously written about their practice so this book has provided deeper connection with a variety of different practitioners and with clients, to widen the discourse regarding relational healthcare. They have reflected on their experiences and given us a privileged insight into how they have coped with these demands.

Altered Power Balances

Community-based healthcare usually takes place in the client’s home. This brings with it a change in the power dynamic between client and health professional. Acute care usually takes place in settings such as hospitals where health professionals are on home ground, where they can feel comfortable as it is their familiar territory and the resources they need are generally all at hand. This power dynamic is somewhat reversed in home settings, where practitioners are really guests in their clients’ homes (Heckman & Cott, 2005). This is literally the clients’ home territory, where they can expect to feel comfortable and health professionals
can even be seen as a kind of intruder. Managing this intrusion takes sensitivity on the part of health professionals who are entering a “sacred space”.

The health professional has to earn the trust and acceptance of the client, even though the visitor is the one with the clinical power and knowledge. The visitor’s expertise cannot be simply imposed on a client. It can also take some time to earn the trust and acceptance needed and health professionals often have to exercise a form of patience not as often needed in acute care.

THE IMPORTANCE OF TIME

The importance of time was another theme that frequently occurred across the chapters. One author (a client) commented on the turnover of health professionals that occurred every few months and the time and the work it needed (on his part) to teach the newcomers how he wanted things done, and what he knew worked for him. The time required for communicating and learning about practical matters was complicated by the need to develop professional working relationships with the newcomer where the trust and acceptance, mentioned above, had to be redeveloped all over again.

There is a strong case for arguing that many of these therapeutic relationships should be long term, once the trust and acceptance have been established. However, there can be no complacency in long-term relationships. As Bakhtin (1981) reminds us, relationships are never static. They are either being made or unmade and health professionals need to be sensitive to how these long-term relationships develop and change over time.

Young clients turn into adults. Elderly clients will eventually decline and approach death. Family carers too change over time and the dynamics of the relationships can become subtly different in ways that can be a challenge. The importance of time and space are also explored in the work of Bakhtin (1984, 1986) who used the term, “chronotope”, and in the work of Schatzki (2010). As noted above, there is usually more change over time among the health professionals, especially if there is a team of these people.

TEAMWORK

The complex needs of many clients are often beyond the capability of one health professional and a team may be required. Such teams can sometimes be surprisingly large. Many clients need someone, some form of case manager, to coordinate the team and ensure the care is comprehensively organised, in a manner that is in the best interests of the client, and that the client is happy with. Such case managers need to be especially skilled at handling the complex relationships that can occur.

One author described how there was a need in one case to coordinate the work of three occupational therapists, who were funded by different organisations to take on different aspects of a client’s care. This was in addition to all the work required from a long list of other health professionals. These team leaders may need to have
the ability to act as an advocate for the client when things go wrong and be willing to confront organisations or individuals who have not provided adequate care for their clients. Teams can also include the network of family and friends who provide care and support for the clients as people and may also be involved in providing healthcare. As we saw, in the chapter on death and dying, these teams work well when the members can support each other so that those clients who wish to die at home can be enabled to do so. Complicating this matter of family support, is the controversial issue of balancing decisions about what is the best choice of care (based on standard evidence-for-practice) with decisions relating to what is in the best interests of a client.

**ADVOCATING FOR AUTONOMY AND EQUALITY**

*Dignity of Risk*

Some of the authors raised the issue of the quality of life of a client. There can be issues between providing care that keeps clients safe versus care that allows clients to lead a relatively normal life. This is generally referred to as “dignity of risk”. We heard the story of the client who set great store in being able to close her curtains each night. The care worker used a “handled belt” to help the client perform this nightly ritual which gave the client great satisfaction. However, it could be argued that this put the client at risk as there was always a chance that the care worker’s grasp could have slipped and the client might then have fallen.

However, refusing to let the client close the curtains would clearly have caused her great distress. This is part of a wider issue, best exemplified in debates about care of the elderly. According to Gawande (2014) there are millions of unhappy elderly people around the world who are “in care” and who are deeply unhappy with that care. This, it is argued, is because their carers insist that the elderly should always be “safe”. Gawande makes a strong argument that taking some risk and allowing these people to try and live a more normal life makes them much happier, even if the chance of an untoward event is increased.

This issue of finding a balance between providing a completely safe environment and one that permits a normal life, but with some risk, is likely to confront the health professions and the wider society for some time to come. Very often these decisions are presented as choices that people must make about the healthcare they want for themselves or their relatives. However, it is not always as simple as that.

*“Logic of Choice” Versus the “Logic of Care”*

Mol (2006) questions the discourse around what she calls the “logic of choice” versus the “logic of care”. Essentially, she critiques the positioning of the recipients of healthcare as if they were simply consumers (clients) who can, and should, make choices about their healthcare, just as if they were buying consumer goods in a shop. In the logic of choice the values that predominate are autonomy.
and equality. This is equality in the sense of individuals having equal opportunities alongside professional healthcare providers for making their own choices.

Mol points out that there is also an assumption that the ethical responsibility for whatever may follow will then fall on the shoulders of the clients, because they “chose” the healthcare “packages” that they receive. Mol contrasts this attitude with what she calls the “logic of care”. In the logic of care the values that are emphasised are attentiveness to the real needs of specific people and providing the best care. What is “best” has to be worked out for each individual and, where possible, negotiated with each individual. These different sensitivities to how we conceptualise care, and enact it, for different people relate to another issue, which is the need for practice wisdom.

**PRACTICE WISDOM**

The contributors to this book are mostly very experienced practitioners. Their insights provide support for the idea that with this experience comes wisdom, in this case what can be called practice wisdom. By reflecting on the subtle differences between cases they have developed a sensitivity that allows them to customise the care they provide for each client. Their personal experience of practice has been turned into personal expertise. They seem to have developed what Aristotle (1999) called phrónēsis, which we discussed in an earlier chapter, and is defined as the disposition to act wisely.

Through practice wisdom there is a sharpened awareness of how the particular circumstances of each case require the modification of standard procedures. The wisdom to make client-centred decisions about such modifications comes through reflecting on the insights and discernments gained from dealing with many cases with all their glorious differences.

The practitioners in this book seem to have taken to heart the advice of Sackett, Richardson, Rosenberg, and Haynes (1996) when they pioneered the evidence-based medicine/practice movement. The advice was to integrate the best available evidence with the personal experience and expertise of the practitioner along with the values and desires of the client. While the wider world of healthcare seems to have focused nearly all of its attention on the best available evidence, to the exclusion of all else, it is clear that the practitioners in this book have clearly recognised the importance of the client’s values and desires. It is also clear from the contributions to this book that although practitioners need considerable experience, and need to reflect on that experience if they are to turn their experience into expertise, this process is expedited if they have a mentor who can help them reflect and draw out the lessons that can be learned. One of the most important ways in which their expertise is developed and shared is through narrative.
A FINAL WORD

Narratives of Care

Sensitivity to narrative aspects of professional relationships and healthcare also seems to underpin many of the accounts and experiences related in this book. These practitioners do not simply deliver “care” in a technical rational manner. Through the relationships they develop they want to know the answers to some key questions: What story is the client living out? What story does the client want to live out? What story can the client live out? This relates to the concept of a “logic of care” discussed above. A caring approach will strive to help clients live out the best story they can rather than let them simply make choices that may be ill-advised, and that absolve the health professional of all responsibility. “If things don’t go well then it’s the client’s fault. They chose it”.

The practitioners in these pages care for their clients without being paternalistic. This is true practice wisdom in action. We have already noted in an earlier chapter some of the key points of adopting a narrative approach to healthcare. By adopting a caring approach practitioners become part of the story that their clients live out and the clients become part of the story that the practitioners live out. Becoming involved in this kind of work is not just a job. It becomes a way of life. The insights in this book reinforce current work in narrative medicine where there is a growing realisation of the importance of the intersubjectivity that connects practitioner and client. Take for example this quote:

We want clinicians to come to appreciate the importance of the emotion and intersubjective relations borne of the telling and listening that occur in any clinical encounter. And we hope for patients that our work might open up healthcare to more trust, more accurate knowledge about one another, and more justice. (Charon et al., 2017, p. 2)

EMBODIED PRACTICE

The practitioners in this book do not seem to undertake community-based healthcare as simply a job to be done. It could be argued that there are three axes to their practice. The first axis is what they know, the specialised knowledge such as the biomedical sciences that form an important basis for nearly every health profession. The second axis is the technical know-how of being able to skilfully perform physical procedures, such as mobilising patients who have difficulties moving. Both these axes have to be mastered by the practitioners if they are to be regarded as competent. However, there seems to be a third axis, which could be described as being/becoming.

These practitioners do not simply know about things like ethics or how to go through the motions of doing ethics. They are ethical practitioners. Likewise, they are caring and professional. These are qualities of being. These qualities are a part of who and what these people are. There is therefore an ontological aspect to their practice as well as the conventional epistemological aspect that is preoccupied with
what they know, cognitively, “in their heads” along with the technical procedures they can perform.

The best way of expressing this is to say that there is much about their practice that is embodied within them. What they know “in their heads”, and what they can do and how they act, is also a part of them in a way that is more fundamental than simply what they know from textbooks.

A Way of Being in the World

Being this kind of practitioner is a way of being in the world. Their personal expertise, their practice wisdom, is developed from their own practice experience in a deeply personal way that becomes a part of their identity. In order to ensure that these kinds of practitioners continue to enter the workforce our professional education needs to address these three axes. The first two axes, textbook knowledge and technical procedures, already receive a lot of attention, but the third tends to be ignored.

However, there have been calls for some time for professional education to become more attuned to the need to develop the ontological aspect of professional practice – the being and becoming part (Barnett & Coate, 2004). This approach to professional education is based on the neo-Aristotelian approach, touched on earlier, with its emphasis on epistêmê (propositional knowledge) tékhē (technical procedures) and phrônēsis, (the disposition to act wisely).

This kind of education is not easy, but we hope that the insights in this book will further the awareness that professional practice, and its education, are complex and that the complexity includes the ontological. The move to develop reflective practitioners, who can be aware of how their practice changes them, can be seen as a step in this direction (Schön 1983, 1987). If the demand for community-based healthcare continues then there is going to be a growing need for health professionals who can embrace all three aspects of their practice and who can truly offer the care that will be needed.

CONCLUSION

The perspectives of all the different contributors to community-based healthcare flow through this book, creating dialogue between the co-authors and with you the reader. The chapter authors are mostly community-based practitioners, speaking from practice about what they consider to be important themes of care in relational approaches to community-based healthcare. This thinking was stimulated by the Mindful Dialogues PhD work done by Diane and supervised by Stephen and Joy. We hope that the mindful dialogues, which we studied and conducted together have been mirrored by the dialogue between the authors and co-authors. We encourage you to enter into dialogue with the people you meet, especially the people you disagree with – listen to their stories and tell them your own.
REFERENCES


Stephen Loftus PhD
Oakland University
Michigan, USA

Diane Tasker PhD
Education, Practice and Employability Network, Australia
CONTRIBUTORS

Suzanne Alder PhD
Health Psychologist
Bathurst, Oberon, NSW, Australia

Chris Atkins RN PhD MACN
Educator, Royal Rehab College
Ryde, NSW, Australia

Tania De Bortoli PhD
Speech Pathologist, Post-doctoral Research Academic
The University of Newcastle, Australia

Helen Butlin
Doctoral Candidate, University of Western Ontario
Registered Psychotherapist & Specialist in Spiritual Care
London Regional Cancer Program, London Health Sciences Centre
London, Ontario, Canada

Bronwyn Couch MSpecEd
Occupational Therapist
Hazelbrook, Australia

Anne Croker PhD
Research Fellow, Department of Rural Health
The University of Newcastle, Australia
Partner, Education, Practice and Employability Network, Australia

Alfred De Leeuw
Physiotherapist
Penrith, NSW, Australia

Helen Fenech RN
New South Wales, Australia

Jackie Finlayson RN
New South Wales, Australia

Maria Fitzgerald CMHN. RN, MN(Hons), MN(Mental Health)
Katoomba, Australia

Katriona Herborn MBBS, FRACGP, DipObs, MPM(Uni of NSW), FACPM
General Medical Practitioner
Katoomba, NSW, Australia
CONTRIBUTORS

Joy Higgs AM PhD PFHEA
Director, Education, Practice and Employability Network, Australia
Professor in Higher Education
Charles Sturt University, Australia

Debbie Horsfall PhD
School of Social Sciences and Psychology
Western Sydney University, Australia

Mark Horton
Wagga Wagga, New South Wales, Australia

Gabrielle Klymenko BHlthSc(Hons)/MOT
Occupational Therapist
Sydney, Australia

Stephen Loftus PhD
Associate Professor
Oakland University William Beaumont School of Medicine
Rochester, MI, USA

Kathleen McCarthy MBBS, Dip MSK, MScSoc, FAFRM (RACP)
Consultant Rehabilitation Physician
Sydney, Australia

Jane Meiklejohn BAppSc(OT)
Occupational Therapist and Case Manager
NSW, Australia

Catherine Murray OAM
Wentworth Falls, Australia

Diane Tasker PhD
Partner, Education, Practice and Employability Network, Australia

Angie Titchen DPhil (Oxon), MSc, MCSP
Visiting Professor, University of Ulster, Northern Ireland

Sharyn Williams RN
Senior Care Assessor
Southern Cross Community Healthcare, NSW, Australia
PRACTICE, EDUCATION, WORK AND SOCIETY

Volume 1
WRITING QUALITATIVE RESEARCH ON PRACTICE (2009)
Joy Higgs, Debbie Horsfall, and Sandra Grace (Eds.)

Volume 2
RESEARCHING PRACTICE (2010)
A discourse on qualitative methodologies
Joy Higgs, Nita Cherry, Robert Macklin, and Rola Ajjawi (Eds.)

Volume 3
EDUCATION FOR FUTURE PRACTICE (2010)
Joy Higgs, Della Fish, Ian Goulter, Stephen Loftus, Jo-Anne Reid, and Franziska Trede (Eds.)

Volume 4
INNOVATIONS IN ALLIED HEALTH FIELDWORK EDUCATION (2010)
A critical appraisal
Lindy McAllister, Margo Paterson, Joy Higgs, and Christine Bithell (Eds.)

Volume 5
CREATIVE SPACES FOR QUALITATIVE RESEARCHING (2011)
Living research
Joy Higgs, Angie Titchen, Debbie Horsfall, and Donna Bridges (Eds.)

Volume 6
PRACTICE-BASED EDUCATION (2012)
Perspectives and strategies
Joy Higgs, Ronald Barnett, Stephen Billett, Maggie Hutchings, and Franziska Trede (Eds.)

Volume 7
REALISING EXEMPLARY PRACTICE-BASED EDUCATION (2013)
Joy Higgs, Will Letts, Dale Sheehan, Julie Baldry Currnes, and Gail Jensen (Eds.)

Volume 8
EDUCATING HEALTH PROFESSIONALS (2013)
Becoming a university teacher
Stephen Loftus, Tania Gerzina, Joy Higgs, Megan Smith, and Elaine Duffy (Eds.)

Volume 9
HEALTH PRACTICE RELATIONSHIPS (2014)
Joy Higgs, Anne Croker, Diane Tasker, Jill Hummell, and Narelle Patton (Eds.)
Volume 10
PROFESSIONAL PRACTICE DISCOURSE MARGINALIA (2016)
Joy Higgs and Franziska Trede (Eds.)

Volume 11
COLLABORATING IN HEALTHCARE (2016)
Reinterpreting therapeutic relationships
Anne Croker, Joy Higgs, and Franziska Trede (Eds.)