CHAPTER 1

Introduction

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Since publishing \textit{Person-Centred Nursing: Theory and Practice} (McCormack & McCance 2010) the field of person-centredness in health care has grown significantly. In that short 5-year period, we have seen a burgeoning of interest in the topic, the development of a range of initiatives to promote person-centredness, and an increased volume of research exploring, understanding and evaluating person-centred practices. Person-centred care has a long association with nursing, with a focus on treating people as individuals; respecting their rights as a person; building mutual trust and understanding; and developing therapeutic relationships. However, this has now become a more inclusive health-care philosophy and strategic focus. It is for this reason that we have adopted a more broad-based health-care perspective in this book.

The promotion of ‘person-centredness’ is consistent with health-care policy direction internationally. There have been a number of challenges to the focus on person-centredness in nursing and health care and a view that other approaches such as relationship-centred care, compassionate care and even dignified care are more appropriate frameworks for expressing an inclusive family and community approach to what can generally be understood as holistic care practices. However, none of these have stood the test of time as ‘alternatives’ but instead are increasingly seen as components of person-centred nursing and health care, or as constructs that explain different dimensions of person-centredness. This goes some way to affirming the importance of person-centred approaches, not just as care practices in particular professional groups, but as a philosophical underpinning of health-care systems that places people at the centre.

This endorsement of people at the centre of care systems is particularly exemplified by the World Health Organization, which has set out a comprehensive framework of people-centred health services. They describe people-centred health services as

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... an approach to care that consciously adopts the perspectives of individuals, families and communities, and sees them as participants as well as beneficiaries of trusted health systems that respond to their needs and preferences in humane and holistic ways.

People-centred care requires that people have the education and support they need to
make decisions and participate in their own care. It is organized around the health needs and expectations of people rather than diseases.

World Health Organization (2015; p. 10)

This all-encompassing description of people-centredness calls for the delivery of health services that are organised, managed and delivered in a way that ensures people as individuals, communities and populations are at the heart of planning and policy making. It challenges health-care practitioners to think of the person first and then the disease. It requires governments to ensure that people have access to health-care services that reflect their needs, promote health, manage disease, support self-management of long-term conditions and in which people are educated about health in order to maximise well-being. The ‘person’ is at the heart of the WHO policy framework, and whilst it is a demanding ‘ask’ of nations all over the world to consider individual needs, many of which are at different stages of development of their health-care systems, the intention is that of a global movement in person-centredness.

The WHO has a global goal of humanising health care by ensuring that health care is rooted in universal principles of human rights and dignity, non-discrimination, participation and empowerment, access and equity, and a partnership of equals:

The overall vision for person-centred health care is one in which individuals, families and communities are served by and are able to participate in trusted health systems that respond to their needs in humane and holistic ways…

World Health Organization (2007, p. 7)

Many countries are embracing this challenge, and health-care policy and strategy initiatives are focused on reorganising for people-centredness. The Health Foundation (2015a, 2015b) has been central to many of these strategic developments and ensuring that, at least at the level of health systems, people are at the centre of care:

We want a more person-centred healthcare system, where people are supported to make informed decisions about and to successfully manage their own health and care, and choose when to invite others to act on their behalf … We want healthcare services to understand and deliver care responsive to people’s individual abilities, preferences, lifestyles and goals.

The Health Foundation (2015a)

The Health Foundation has produced a range of resources to enable an increased understanding of person-centred care and to support its development across the whole health-care system (The Health Foundation, 2015b). In the United Kingdom for example, person-centredness has been at the heart of health-care policy and strategy developments, through initiatives in England such as the ‘personalisation agenda’ (Department of Health, 2010), the ‘1000 Lives+ campaign in Wales (http://www.1000livesplus.wales.nhs.uk/pp-driven-care) and the Person-centred Health and Care Collaborative in Scotland (http://www.qihub.scot.nhs.uk/person-centred/person-centred-health-and-care-collaborative-.aspx). In Northern Ireland, the Service Framework for Older
People is based on person-centred values and principles and has person-centred care at the heart of its quality framework.

In other countries such as Norway, Canada, the United States, Australia and Denmark, person-centredness forms the basis of health-care reform that is focused on humanising health-care systems and how care is provided – cf. Impact NSW (2008), Department of Health and Human Services (2012), Norwegian Ministry of Health and Care Services (2009), Alzheimer Society Canada (2014), and Healthcare Transformation and Integrated Care in Denmark (Henrikson 2015). These strategies and frameworks influence the delivery patterns of health care and ways in which practice is developed.

Despite all of these developments the focus continues to be on ‘care’ and less on how organisations create person-centred cultures. There is much still to be done in developing health-care cultures towards ones that truly place people at the centre of their care in order to achieve effective and meaningful outcomes. Richards et al. (2015, p. 3) suggest that it is ‘time to get real about delivering person-centred care’ and argue that it requires a sea change in the mindset of health professionals and patients/clients alike. Part of this need for change is a move away from the discourse of person-centred care to that of person-centred cultures. Over the past 10 years, nursing and health-care practice have been dominated by negative reports of poor, undignified, uncompassionate and at times inhumane care, particularly of older people, people living with learning/intellectual disabilities and other vulnerable adults. In all of the investigations into these breaches of what counts as acceptable care standards, the issue of care culture has been identified as a key issue. Whilst highlighting unacceptable practices, these reports all raised the significance of ‘culture’ and its influence on the experiences of care workers, service users and families. However, whilst culture has been highlighted, the proposed solutions reflect a continued managerialist-led agenda and a philosophy of ‘training’ of staff for change. However, increasing evidence (Davies 2002; Scott et al. 2003; Carlström & Inger 2012; McCance et al. 2013; Laird et al. 2015) demonstrates that bringing about culture change requires significant and deep change of patterns in organisational systems and approaches to change that are founded on humanistically derived principles of adult learning. Person-centredness can only happen if there are cultures in place in care settings that enable staff to experience person-centredness and work in a person-centred way. With a focus on culture, we adopt the following definition of person-centredness; the origins of this definition will be elucidated further in Chapter 3:

... an approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development.

This definition is relationship-orientated, but includes all relationships in any health-care situation or context. The focus on healthfulness is consistent with
contemporary theories of well-being and wellness as health goals, and reflects the diversity of relationships that people experience. Effective cultures have clearly articulated and shared values and so this definition is also clear about the kinds of values that are important in a person-centred culture. Finally, we argue through this definition that creating a person-centred culture is not a ‘one-off’ event that can be achieved through a short-term project or education/training programme. Instead it requires an ongoing and sustained commitment to culture enhancement through participatory, collaborative and inclusive approaches to development.

The WHO suggests that there are a range of issues to be addressed in order to make health-care systems more people-centred, including:

- Empowering and engaging people.
- Strengthening governance and accountability.
- Reorienting care models towards efficiency and effectiveness.
- Coordinating services around the needs of people, health-care provider integration and effective networks.
- Creating an enabling environment for change.

As well as using our definition of person-centredness as a ‘rudder’ to guide our thinking when planning this book, we also in this book address many of the issues identified by the WHO as significant in developing people-centred health-care systems. Chapter contributors focus on strategic and systems-level developments, management and leadership responsibilities, advancing models of care, as well as illustrating a variety of strategies that can be used to go ‘deep’ into the culture of teams and organisations in order to develop person-centred cultures.

A focus on developing person-centred cultures does not in any way negate the need to reaffirm the importance of the fundamentals of care, emphasised in publications over the past 10 years or so (e.g. Royal College of Nursing 2010), all of which highlight the challenges for nurses and midwives in providing sensitive and dignified care. The continued drive, however, within most health systems to demonstrate effectiveness and efficiency through performance management processes challenges developments in person-centred nursing and health care. A range of quality and clinical indicators have been developed, many of which pay little attention to how patients, clients and their families experience care but instead are focused on measuring performance and effectiveness (Maben et al. 2012). Whilst nurses have a significant contribution to make in determining positive patient experience, the evidence demonstrates that greater emphasis continues to be placed on quantified measurement of indicators rather than a focus on those that evaluate the impact of nursing and midwifery care, with a person-centred orientation (McCance et al. 2012). In this context, we argue that the time is ripe for promoting new ways of working that can deliver effective person-centred practices, using approaches that can demonstrate positive outcomes as a result, and working with indicators that show the emergence and sustaining of person-centred cultures of effectiveness.
Since 2001, we (B.M and T.M) have been working with the Person-centred Nursing Framework as our approach to articulating the dynamic nature of person-centredness, as well as its complexity at the levels of culture and systems. Since that time, this framework has grown and developed and has made a significant contribution to the landscape of person-centredness globally.

The Person-Centred Nursing Framework and its evolution

The Person-Centred Nursing Framework was originally developed by McCormack and McCance (2006) and was derived from previous empirical research focusing on person-centred practice with older people (McCormack 2001) and the experience of caring in nursing (McCance et al. 2001). The original framework comprised four constructs:

1. **Prerequisites**, which focus on the attributes of the nurses.
2. **Care environment**, which focuses on the context in which care is delivered.
3. **Person-centred processes**, which focus on delivering care through a range of activities.
4. **Outcomes**, the central component of the framework, are the results of effective person-centred nursing.

We suggested that in order to deliver positive outcomes for patients, families and staff, account must be taken of the prerequisites and the care environment, which are necessary for providing effective care through person-centred processes. In 2010, *Person-Centred Nursing: Theory and Practice* (McCormack & McCance 2010) provided a more comprehensive explanation of the four constructs that comprise the Person-Centred Nursing Framework and the core elements within each construct.

Since the publication of the framework, its reach has been worldwide, with it being translated into several different languages and tested in several different contexts and countries – for example, McCormack, B. and McCance, T. (2013) Personcenterad omvårdnad. In: J. Leksell and M. Lepp (eds) *Sjuksköterskans Kärnkompetenser*, Liber Publishers, Stockholm, pp. 81–110. The framework has been used as a guide for the structuring of implementation studies that have focused on the development of person-centred nursing in a variety of contexts. Through the use of the framework in this way, we have been able to identify and refine relationships between concepts as well as identify new areas of research. We have undertaken implementation studies in residential care settings for older people, in a variety of secondary and tertiary care settings, in community care and in palliative care (see McCormack et al. 2010; Yalden & McCormack 2010; McCance et al. 2011). In these studies, the framework has been used to promote an increased understanding of person-centred nursing with the aim of enabling practitioners to recognise key elements in their practice, generate meaning from data that can inform the development of person-centred nursing, and most
importantly to focus the implementation and evaluation of developments in practice.

A number of instruments have been developed through these studies, all of which have enabled us to identify key processes in the development of person-centred nursing and resulting outcomes for service users, staff, teams and organisations. We have developed and tested the Person-centred Nursing Index, the Context Assessment Index and the Workplace Culture Critical Analysis Tool (Slater et al. 2009, 2010; McCormack et al. 2009a, 2009b) and most recently, the Person-centred Practice Inventory (Slater et al. 2015). These instruments have been used in a variety of international studies that have shown outcomes from the implementation of person-centred nursing. The systematisation of other processes such as the collection of ‘patient stories’ has also emerged through this research (Laird et al. 2015).

We have also used the framework to influence policy, nationally and internationally. In Northern Ireland the framework has been used as the theory of choice to underpin the Chief Nursing Officer’s Nursing Strategy (DHSSPSNI 2010). The Royal College of Nursing adopted the framework to inform its development of ‘Principles of Nursing’ and these are being implemented across the UK (Royal College of Nursing 2010). In the Republic of Ireland the framework has been used to develop a ‘National Practice Development Strategy’ commissioned by the Chief Nurse and which has been implemented throughout the Health Services Executive service areas. This has resulted in changes to how nursing professional development is organised, how care practices are developed and how patient care is delivered (e.g. care in residential long-term care settings; McCormack et al. 2009c, 2010). In Australia, a development programme in over 600 clinical areas that is facilitated by the Chief Nurse of New South Wales Health Department is based on the Person-centred Nursing Theoretical Framework (Wilson & Cross 2013). These high-profile implementation studies in Northern Ireland, The Republic of Ireland and in Australia are examples of national programmes of work that have been based on the Person-centred Nursing Framework. These programmes of implementation research have involved working collaboratively with large numbers of practitioners, patients/clients, families and service managers and have shown improved outcomes:

• in the ways in which nursing and health-care practices are delivered (such as pain management postoperatively in acute care, and the management of mealtimes in residential settings);
• in the way that the culture of participating practice settings has been improved to support more person-centred ways of working (such as improved leadership, better care coordination and more effective teamwork);
• in the care experiences of patients/clients (such as increased ‘hope’, more dignified care and more involvement in care); and
• in the way that staff experience person-centredness in the workplace (such as increased commitment, role clarification, more effective communication and more access to ongoing professional development).
It has also been exciting to observe the increasing number of universities that are adopting the framework as the framework of choice to underpin education curricula. The research underpins the curriculum for masters students in nursing at the University of Sydney and the undergraduate nursing curricula at the Ulster University Northern Ireland, and University College Dublin, Republic of Ireland. In New Zealand the Person-centred Nursing Theoretical Framework has been adapted to inform a new learning framework for continuing specialty nursing education over three District Health Boards in the Lower North Island. In Queen Margaret University, Edinburgh, the framework has been developed as the philosophical framework underpinning the new masters level Person-centred Nursing Framework (incorporating specialist routes in health visiting, school nursing and district nursing). Finally in Norway, the framework underpins the first ever doctoral education programme in Person-centred Healthcare at Buskerud and Vestfold University College.

In the context of doctoral education, we have had the privilege of supervising a range of doctoral students, many of whom are chapter authors in this book, and who have all based their work (conceptually and theoretically) on the Person-centred Nursing Framework. This work has been undertaken in a variety of settings, care contexts and countries. Not only have these doctoral candidates used the Person-centred Nursing Framework, but also they have tested and refined key elements, challenged underpinning concepts, informed key changes to the framework and advanced knowledge in the field. Many have developed new models and frameworks that extend our original thinking and that in themselves offer new perspectives into the development of person-centredness in different health-care contexts.

All of this work has enabled the continued testing of the framework in practice, the refinement of key elements of the framework as the evidence base increases and the evaluation of its effectiveness as a framework for developing person-centred cultures. Our work in this period has become increasingly multi-disciplinary and multi-professional in its focus and so too has our framework. In this book therefore we adopt a multi-disciplinary and multi-professional approach and present a new version of the framework, one that has been further refined and is reflective of this change of focus. Whilst the 2010 edition was written solely by the framework authors (McCormack and McCance), in this edition of the book we engage with a wide range of authors, all of whom are connected with the Person-centred Nursing Framework and all of whom are contributing to the advancement of the underpinning knowledge base and the ongoing development and refinement of the framework.

**Structure of the book**

This book is presented in four sections. Section 1 presents a synthesis of the philosophies, concepts and theories that underpin the ‘Person-centred
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Nursing Framework’ and in addition, highlights particular refinements and new additions to the framework in order to move it from a nursing to a more generic health-care focus, and ultimately the first comprehensive presentation of ‘The Person-centred Nursing Framework’.

Section 2 focuses on the infrastructure needed to support person-centred culture development and person-centred practices. It has a particular focus on strategy, leadership and research as key concerns in ensuring the embedding of person-centredness in health-care systems and organisations.

Section 3 specifically addresses the challenges associated with developing person-centred cultures and presents a number of chapters written by people who are all engaged in this kind of work. The section ‘gets inside’ culture and illustrates the depth-work that is needed, the strategies that can be used and the outcomes arising.

In Section 4 we invited a number of collaborators to present their research and development activities in which they make use of the Person-centred Nursing Framework to shape this work. They illustrate the framework being used as a methodology in itself, as a heuristic to guide decision-making and as a tool for practice development. These chapters focus on specific types of care and services but we hope that these can be viewed as illustrative as the principles used by these authors are transferrable across health-care contexts.

We have written this book with a broad target audience in mind, and have tried to ensure that it is accessible to nurses, health-care practitioners and decision-makers working at different levels and across a variety of contexts.

It has been our privilege to work in this field for more than 20 years, and this book reflects the range of activity we have been engaged in as individuals, colleagues and collaborators. The contributors to this book (and many who are not represented here) have in most cases shared that journey (or parts of it) with us. We are truly grateful for their collaboration, cooperation and friendship as well as the high challenge and support offered. It has been these relationships that have shaped what we now publish as the most recent version of the Person-centred Nursing Framework. We know the framework will continue to evolve and grow through these continued relationships, and that is a privilege that we are truly grateful for and which we hope is reflected in the contents of this book.

References


