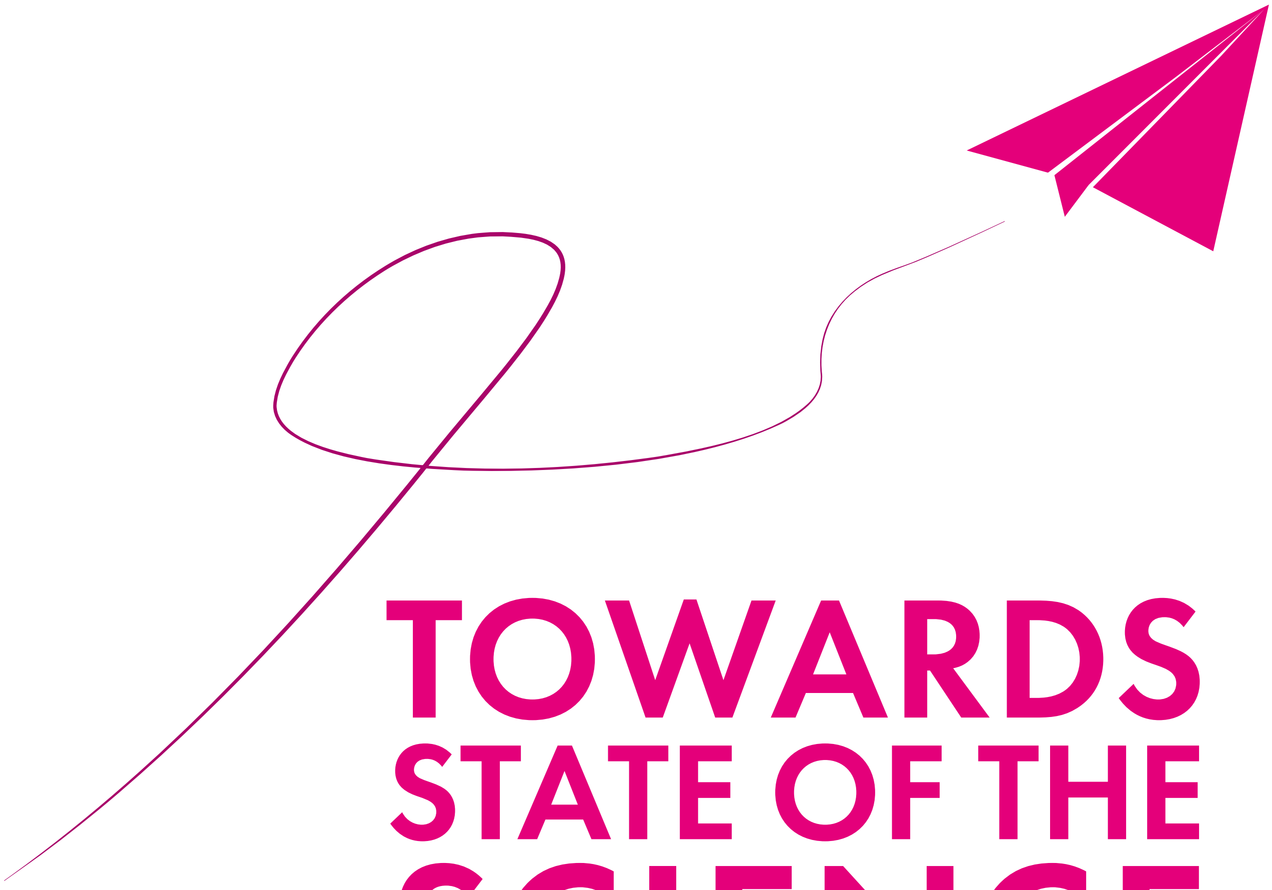
ACTA UNIVERSITATIS GOTHOBURGENSIS
Gothenburg Series in Person-Centred Care 2



TOWARDS STATE OF THE SCIENCE in PERSON-CENTRED CARE

Axel Wolf, Emma Forsgren, Ida Björkman,
David Edvardsson & Joakim Öhlén (Eds)

UNIVERSITY OF
GOTHENBURG

This report provides an overview of the current knowledge of person-centred care and critically illustrates where the theoretical and empirically formed advancement in the field has reached so far. Presentations of brief overviews of four theoretical frameworks and five research literature reviews as related to person-centred care are included as well as commentaries from an international panel who participated in workshops during the first Global Conference on Person-Centred Care (GCPCC) held in Gothenburg, Sweden, in May 2024.

The Gothenburg Series in Person-Centred Care is issued by the University of Gothenburg Centre for Person-Centred Care (GPCC), a Swedish centre of excellence in person-centred care. GPCC conducts clinical and applied interdisciplinary research, and develops methods for implementing and evaluating person-centred care in practice. Its overall vision is sustainable health through sustainable care: to prevent and reduce suffering, and strengthen the efficiency of health care through person-centred care.

Towards State of the Science in Person-Centred Care

Axel Wolf, Emma Forsgren, Ida Björkman, David Edvardsson & Joakim Öhlén (Eds)

UNIVERSITY OF GOTHENBURG

ISBN: 978-91-7963-201-4 (printed)
ISBN: 978-91-7963-202-1 (pdf)
ISSN: 3035-7209

The publication is also available in full text at:
https://hdl.handle.net/2077/84469

Gothenburg Series in Person-Centred Care
Editor: Eric Carlström

Subscriptions to the series and orders for individual copies sent to: Acta Universitatis Gothoburgensis, PO Box 222, SE-405 30 Göteborg, Sweden or to acta@ub.gu.se

Cover:
Art by designer Pamela Lindgren, Gothenburg.

Print:
Stema, Borås, Sweden, 2024.

Abstract in English

Title: Towards State of the Science in Person-Centred Care
Editors: Axel Wolf, Emma Forsgren, Ida Björkman, David Edvardsson & Joakim Öhlén (Eds)
Language: English
ISBN: 978-91-7963-201-4 (printed)
ISBN: 978-91-7963-202-1 (pdf)
ISSN: 3035-7209
Keywords: delivery of health care; health; health communication; health systems; interdisciplinary research; illness; interprofessional relations, patient care team; patient-centred care; person-centred care; quality of healthcare

This report aims to take first steps in reporting the state of the science in person-centred care: an idea focusing on how health professionals, patients and their family carer(s) collaboratively plan and carry out care. Having been introduced in the literature and in the field of health care in the late 20th century, the concept of person-centred care has expanded since the millennium shift into an interdisciplinary field of research and interprofessional practice that goes beyond professional healthcare and includes informal care by family carers, communities and larger civil society. The goal of this report is to provide an overview of the current knowledge of person-centred care and to critically illustrate the theoretical and empirical advancement of the field so far. A total of 68 international scholars have contributed, all of whom participated in the first Global Conference on Person-Centred Care (GCPCC) held in Gothenburg, Sweden, in May 2024. This report presents brief overviews of four theoretical frameworks and five research literature reviews related to person-centred care, followed by commentaries on the state of the science in person-centred care. These come from an international panel who participated in workshops held at the GCPCC which focused on the core theoretical foundations for person-centred care, and modes and strategies for translating person-centred care into practice. Finally, the report concludes with two reflective chapters, one relating person-centred care to precision health, and one on ways forward in the field to a comprehensive understanding of the state of the science in person-centred care.

Abstract in Swedish

Titel:	Towards State of the Science in Person-Centred Care
Redaktörer:	Axel Wolf, Emma Forsgren, Ida Björkman, David Edvardsson & Joakim Öhlén
Språk:	English
ISBN:	978-91-7963-201-4 (printed)
ISBN:	978-91-7963-202-1(pdf)
ISSN:	3035-7209
Nyckelord:	hälso- och sjukvård; hälsa; hälsokommunikation; hälso- och sjukvårdssystem; tvärvetenskaplig forskning; sjukdom; relationer mellan yrkesgrupper, vårdteam; patientcentrerad vård; personcentrerad vård; vårdkvalitet

Denna rapport syftar till att ta steg emot att sammanfattande förstå kunskap om personcentrerad vård, vilket på engelska kan benämnas State of the Science. Personcentrerad vård utgår från en idé om att fokusera hur vårdpersonal, patient och deras närstående tillsammans planerar och genomför vård. Idén kan i litteraturen och inom hälso- och sjukvård spåras till senare hälften av förra seklet. Efter millennieskiftet har det utvecklats till ett flervetenskapligt forskningsområde och tvärprofessionell praktik, vilket spänner från professionell hälso- och sjukvård och omsorg till informell vård och omsorg av närstående, nätverk och civilsamhället. Målet med denna rapport var att ge en överblick över den nuvarande kunskapen om personcentrerad vård och att kritiskt visa teoretiskt och empiriskt utvecklad kunskap om personcentrerad vård. Totalt har 68 internationella deltagare bidragit till rapporten och alla deltog vid den första Global Conference on Person-Cenetred Care (GCPCC) som hölls i Göteborg i maj 2024. Rapporten presenterar korta översikter av fyra teoretiska ramverk och fem litteraturöversikter av forskningslitteratur avseende personcentrerad vård. Detta följs av kommentarer om kunskapsläget vad gäller personcentrerad vård från en internationell panel som deltog i workshops under GCPCC. Dessa kommentarer berör teoretiska grunder för personcentrerad vård samt metoder och strategier för att omsätta personcentrerad vård i praktiken. Rapporten avslutas med två reflekterande kapitel, ett som relaterar personcentrerad vård till precisionshälsa, och ett om framtida steg emot att sammanfattande förstå kunskap om personcentrerad vård.

Contents

Acknowledgements

This report derives from presentations and workshops held at the first Global Conference on Person-Centred Care (GCPCC) in Gothenburg, Sweden, in May 2024. The organiser of the conference was the University of Gothenburg Centre for Person-Centred Care (GPCC) in Gothenburg, Sweden.

Established in 2010, the GPCC is a national interdisciplinary and cross-faculty research centre driven by the vision of sustainable health through sustainable care, which entails preventing and reducing suffering, and strengthening the efficiency of health care through person-centred care. The GPCC is funded by the Swedish Government's grant for Strategic Research Areas, Care Sciences, and co-funded by the University of Gothenburg, Sweden.

The manuscript for this report was professionally language edited by Anita Shenoi.

Presentation of authors

Editors

Ida Björkman, PhD, Associate Professor, The University of Gothenburg Centre for Person-Centred Care (GPCC) and Institute of Health and Care Sciences, Sahlgrenska Academy at the University of Gothenburg, Gothenburg, Sweden.

David Edvardsson, PhD, Professor, School of Nursing and Midwifery, La Trobe University, Australia; University of Gothenburg Centre for Person-Centred Care, Gothenburg University, Gothenburg, Sweden.

Emma Forsgren, PhD, Researcher, The University of Gothenburg Centre for Person-Centred Care (GPCC) and Institute of Health and Care Sciences, Sahlgrenska Academy at the University of Gothenburg, Gothenburg, Sweden.

Axel Wolf, PhD, Professor, The University of Gothenburg Centre for Person-Centred Care (GPCC) and Institute of Health and Care Sciences, Sahlgrenska Academy at the University of Gothenburg, Gothenburg, Sweden; Institute of Nursing and Health Promotion, Oslo Metropolitan University, Oslo, Norway; Department of Anesthesia, Operation and Intensive Care, Sahlgrenska University Hospital/Östra, Region Västra Götaland, Gothenburg, Sweden.

Joakim Öhlén, PhD, Professor, The University of Gothenburg Centre for Person-Centred Care (GPCC) and Institute of Health and Care Sciences, Sahlgrenska Academy at the University of Gothenburg, and The Palliative Centre, Sahlgrenska University Hospital, Gothenburg, Sweden.

Authors of framework presentations

Inger Ekman, PhD, Professor, Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Sweden; University of Gothenburg Centre for Person-Centred Care (GPCC), University of Gothenburg, Sweden; Department of Medicine, Geriatrics and Emergency Medicine, Sahlgrenska University Hospital/Östra, Gothenburg, Region Västra Götaland, Sweden.

Brendan McCormack, Professor, Head of School and Dean, The Susan Wakil School of Nursing and Midwifery (including Sydney Nursing School), Faculty of Medicine and Health, The University of Sydney, Australia.

Maria J. Santana, PhD, Professor, Departments of Pediatrics and Community Health Sciences, Cumming School of Medicine, University of Calgary, Alberta, Canada.

Viktoria Stein, Assistant Professor, The Department of Public Health and Primary Care, Leiden University Medical Centre, the Netherlands.

Authors of reviews

Camilla Anker-Hansen, PhD, Associate Professor, Faculty of Health, Welfare and Organisation, Østfold University College, Fredrikstad, Norway.

Dion Candelaria, PhD, RN; Faculty of Medicine and Health, Susan Wakil School of Nursing and Midwifery (Sydney Nursing School), Australia.

Zahra Ebrahimi, PhD, University of Gothenburg Centre for Person-Centred Care (GPCC) and Institute of Health and Care Sciences, Sahlgrenska Academy at the University of Gothenburg, Sweden.

Inger Ekman (see above, Authors of frameworks).

Hadeel Elhassan, MScPh, University of Gothenburg Centre for Person-Centred Care (GPCC), Sahlgrenska Academy, University of Gothenburg, Sweden.

Caroline Feldthusen, The University of Gothenburg Centre for Person-Centred Care (GPCC), Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden, and Department of Occupational Therapy and Physiotherapy, Sahlgrenska University Hospital, Gothenburg, Sweden.

Ingrid Femdal, PhD, Associate Professor, Faculty of Health, Welfare, and Organisation, Østfold University College, Fredrikstad, Norway.

Emma Forsgren, (see above, Editors).

Robyn Gallagher Sydney Nursing School, Faculty of Medicine and Health, University of Sydney, Australia.

Hanna Gyllensten, PhD, Associate Professor, The University of Gothenburg Centre for Person-Centred Care (GPCC) and Institute of Health and Care Sciences, Sahlgrenska Academy at the University of Gothenburg, Sweden.

Jeroen M Hendriks, Caring Futures Institute, College of Nursing and Health Sciences, Flinders University; Centre for Heart Rhythm Disorders, University of Adelaide and Royal Adelaide Hospital, Australia.

Rasika Hewage, MScPh, University of Gothenburg Centre for Person-Centred Care (GPCC), Sahlgrenska Academy, University of Gothenburg, Sweden.

Lars Kullman, Digital Services, Gothenburg University Library, University of Gothenburg, Gothenburg, Sweden.

Brendan McCormack (see above, Authors of frameworks).

Patricia Olaya Contreras, PhD, The University of Gothenburg Centre for Person-Centred Care (GPCC) and Institute of Health and Care Sciences, Sahlgrenska Academy at the University of Gothenburg, Sweden.

Salma Pardhan, Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Box 457, SE-405 30 Gothenburg, Sweden, University of Gothenburg Centre for Person-Centred Care (GPCC), Sahlgrenska Academy, University of Gothenburg, Sweden, and Department of Biomedical Sciences, Faculty of Pharmaceutical Sciences, KU Leuven, Belgium

Harshida Patel, Associate Professor, Institution of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden.

Richard Sawatzky, PhD, Professor, School of Nursing, Trinity Western University, Langley, and Centre for Advancing Health Outcomes, St. Paul's Hospital, Vancouver, British Columbia, Canada, and Institute of Health and Care Sciences and Centre for Person-Centred Care (GPCC), University of Gothenburg, Gothenburg, Sweden.

Lovisa Thunström, The University of Gothenburg Centre for Person-Centred Care (GPCC) and Institute of Health and Care Sciences, Sahlgrenska Academy at the University of Gothenburg, Gothenburg, and Department of Social Sciences, Marie Cederschiöld University, Stockholm, Sweden.

Tyagi, PhD, MEng, The Susan Wakil School of Nursing and Midwifery, Faculty of Medicine and Health, The University of Sydney, Australia

Sara Wallström, PhD, Associate Professor, The University of Gothenburg Centre for Person-Centred Care (GPCC), Institute of Health and Care Sciences, Sahlgrenska Academy at the University of Gothenburg, Sweden, Department of Forensic Psychiatry, Sahlgrenska University Hospital, Gothenburg, Sweden and Centre for Ethics, Law and Mental Health (CELAM), University of Gothenburg, Gothenburg, Sweden.

Helle Wijk, RN, PHD, Professor, Institute of Health and Care Sciences, The Sahlgrenska Academy at Gothenburg University, and Visiting Professor Department of Architecture and Civil Engineering, Chalmers University of Technology, and Sahlgrenska University Hospital, Gothenburg, Sweden.

Participants and authors of notes from workshops

Camilla Anker-Hansen (see above, Authors of reviews).

Annica Backman, PhD, Department of Nursing, Umeå University, Umeå, Sweden.

Salwan Diwan, Doctoral student, The University of Gothenburg Centre for Person-Centred Care (GPCC) and Institute of Health and Care Sciences, Sahlgrenska Academy at the University of Gothenburg, Sweden.

Anna-Karin Edberg, PhD, Professor, Kristianstad University, Kristianstad, Sweden.

David Edvardsson (see above, Editors).

Inger Ekman (see above, Authors of frameworks).

Ingrid Femdal (see above, Authors of reviews).

Andreas Fors, PhD, Professor, The University of Gothenburg Centre for Person-Centred Care (GPCC) and Institute of Health and Care Sciences, Sahlgrenska Academy at the University of Gothenburg, Gothenburg, Sweden.

Emma Forsgren, (see above, Editors).

Lisa Goldkuhl, Institute of Health and Care Sciences, University of Gothenburg, Sweden.

Brady Granger, PhD, Professor, Duke University School of Nursing, and Duke Heart Nursing Research Program, Duke-Margolis Health Policy Center, Durham, NC, USA.

Hanna Gyllensten (see above, Authors of reviews).

Erna Haraldsdottir, PhD, Professor, Queen Margaret University, Scotland, UK.

Benjamin Harvey MScPh, Doctoral student, The University of Gothenburg Centre for Person-Centred Care (GPCC) and Institute of Health and Care Sciences, Sahlgrenska Academy at the University of Gothenburg, Gothenburg, Sweden.

Angelica Höök, Doctoral student, The University of Gothenburg Centre for Person-Centred Care (GPCC) and Institute of Health and Care Sciences, Sahlgrenska Academy at the University of Gothenburg, Gothenburg, Sweden.

Dominic Jarrett, Learning Disabilities Development Manager, North Ayrshire Health and Social Care Partnership, Scotland, UK.

Kiana Kiani, Doctoral student, The University of Gothenburg Centre for Person-Centred Care (GPCC) and Institute of Health and Care Sciences, Sahlgrenska Academy at the University of Gothenburg, Gothenburg, Sweden.

Anneka Knutsson, PhD, The University of Gothenburg Centre for Person-Centred Care (GPCC) and Institute of Health and Care Sciences, Sahlgrenska Academy at the University of Gothenburg, Sweden.

Anna-Greta Ledin, Licensed Psychologist & Specialist in Clinical Psychology, Representative of the Dementia Association Örnsköldsvik and the former Swedish Alzheimer Association, Örnsköldsvik, Sweden.

Malin Lindberg, The University of Gothenburg Centre for Person-Centred Care (GPCC) and Institute of Health and Care Sciences, Sahlgrenska Academy at the University of Gothenburg, Gothenburg, Sweden.

Stina Mannheimer, The University of Gothenburg Centre for Person-Centred Care (GPCC), Institute of Health and Care Sciences, Sahlgrenska Academy at the University of Gothenburg, Gothenburg, Sweden, PhD student, MD and specialist in General Medicine (author workshops)

Brendan McCormack (see above, Authors of frameworks).

Sarah C Murphy, Atlantic Technological University, Ireland

Christi Nierse, PhD, Fontys University of Applied Sciences, School of People and Health Studies, Eindhoven, The Netherlands

Stefan Nilsson, PhD, Professor, Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, and The University of Gothenburg Centre for Person-Centred Care, and Queen Silvia Children's Hospital, Sahlgrenska University Hospital, Gothenburg, Sweden.

Sepideh Olausson, Institution of Health Care Sciences, Sahlgrenska Academy University of Gothenburg, and Sahlgrenska University Hospital - Department of Anesthesiology and Critical Care, Gothenburg, Sweden.

Salma Pardhan (see above, Authors of reviews).

Harshida Patel (see above, Authors of reviews).

Lotta Pham, RN, MSc, The Palliative Centre, Sahlgrenska University Hospital, Gothenburg, Sweden.

Haverals Reini, Department of Public Health and Primary Care, Faculty of Medicine and Health Sciences. Ghent University, Belgium.

Lena Rosenlund, PhD, Institute of Health and Care Sciences, The University of Gothenburg Centre for Person-Centred Care, Sahlgrenska Academy at the University of Gothenburg and Regional Cancer Centre Stockholm-Gotland, Stockholm, Sweden.

Claudia Silva, Doctoral student, Nursing School of Lisbon, Lisbon, and Nursing Research, Innovation and Development Centre of Lisbon (CIDNUR), Lisbon, Portugal.

Kent Stuber, DC, PhD, Parker University Research Center, Parker University, Dallas, TX, USA, and Canadian Memorial Chiropractic College, Toronto, ON, Canada.

Karl Swedberg, Professor, Department of Molecular and Clinical Medicine. Institute of Medicine, Sahlgrenska Academy, Gothenburg, Sweden.

Kristín Þórarinsdóttir, PhD, Associate Professor, School of Health, Business and Natural Sciences, Faculty of Graduate Studies in Health Sciences, Akureyri, Iceland.

Vaibhav Tyagi (see above, Authors of reviews).

Lovisa Thunström (see above, Authors of reviews).

Sara Wallström (see above, Authors of reviews).

Jakob Wentzer, PhD, National Partnership for Mental Health in Västra Götaland and Gothenburg, and The University of Gothenburg Centre for Person-Centred Care (GPCC) and Institute of Health and Care Sciences, Sahlgrenska Academy at the University of Gothenburg, Sweden.

Filipa Ventura, PhD, The Health Sciences Research Unit: Nursing, Nursing School of Coimbra, Coimbra, Portugal.

Angelica Wiljén, The University of Gothenburg Centre for Person-Centred Care, Gothenburg, and Södra Älvsborgs hospital, Borås, Sweden.

Jacqueline Wilson, RN, PhD Candidate, University of Calgary, Faculty of Nursing, Calgary, Canada.

Acknowledgement of contributions from additional participants in workshops

Amélie Cransac, Department of Pharmacy, University Hospital of Dijon and CTM-Center for Translational and Molecular Medicine, University of Burgundy, Dijon, France.

Bjørg Elisabeth Hermansen, MPhil, RNT, Assistant Professor, Department for Nursing, Health and Laboratory Science, Østfold University College, Fredrikstad, Norway.

Malin Johansson Östrbring, PhD, Pharmaceutical Department, Kalmar County Council, Kalmar, and eHealth Institute, Department of Medicine and Optometry, Linnaeus University, Kalmar.

Cis F.P.C. Lijten, MSc. Fontys University of Applied Sciences, Netherlands.

Tayue Tateke Kebede, Institute of Medicine, University of Gothenburg, Gothenburg, Sweden

Christi Nierse, PhD, Fontys University of Applied Sciences, School of People and Health Studies, Eindhoven, The Netherlands

Alexander Olausson, The University of Gothenburg Centre for Person-Centred Care (GPCC) and Institute of Health and Care Sciences, Sahlgrenska Academy at the University of Gothenburg, Gothenburg, Sweden.

Jon Petter A Stoor, Lávvuo-Research and Education for Sámi Health, Department of Epidemiology and Global Health, Umeå University, Umeå, Sweden.

Asma Sabri, SHARE – Centre for Resilience in Healthcare, Department of Quality and Technology, University of Stavanger, Stavanger, Norway.

Mattias Tranberg, PhD, Institute for Palliative Care, Lund, Sweden

Diana Vareta, MSc, CCRN, Assistant Professor, Egas Moniz School of Health and Science and Egas Moniz Centre for Interdisciplinary Research, Campus University, Quinta da Granja, Caparica, Portugal

1. Introduction

Although healthcare practice has primarily been task and disease oriented, the idea of person-centred care has existed in the literature since the latter part of the last century – an idea focusing on how health professionals, patients and their family carer(s)[1] collaboratively plan and carry out care. This may take place in professional healthcare services, patients' self-care and in informal care by family carers and communities at micro, meso and macro levels. Conceptually, person-centred care emerged in different disciplines, and has thus undergone interdisciplinary and multiprofessional development since its origin. Notably, different terms have been used to describe it, including 'client-centred' (e.g. Rogers, 1961; Townsend, Brintnell & Staisey, 1990), 'patient-centred' (e.g. Balint, 1969; Committee on Quality of Health Care in America, 2001), 'integrated' (e.g. Cloninger et al., 2014; Gröne & Garcia-Barbero, 2001), 'person-centred' (e.g. Dewing, 1999; Leplege et al., 2007; Richards, 1975), and 'people-centred' (e.g. Komatsu, 2008; WHO, 2007) care. Relating the concept to the philosophical notion of 'personhood' (e.g. Kitwood & Bredin, 1992) and, for example, the person's or 'the child's perspective' (e.g. Nilsson et al., 2015) is distinctive. The body of knowledge on person-centred care is now extensive and proliferating, and marked by a combination of empirically based grounded knowledge and major theoretical frameworks.

In the larger literature pertaining to person-centred care (independent of the specific term used), its attributes include being unique, being heard and having a shared responsibility between the patient, their family and health professionals (Feldthusen et al., 2022). The idea of 'person-centred care' is linked to having a meaningful life as the overall goal for the patient's care (Håkansson Eklund et al., 2019).

Aim and goal of the initiative and the report

This initiative aims to take steps towards reporting the state of the science in person-centred care, and has been made especially feasible by having several key

---

[1] 'Health professionals' is here used for personnel, practitioners, clinicians and staff in healthcare services. 'Family carer' is used for significant persons close to the patient (or client), including and beyond relatives and next-of-kin.

scholars in the field participating at the first Global Conference on Person-Centred Care (GCPCC) in Gothenburg, Sweden, in May 2024. Thus, with several scholars present, we had a special opportunity to take steps towards summarising and synthesising what we know and what we do not know about person-centred care, based on current frameworks and reviews of recent research literature. Here we build on the existing literature, and this report briefly presents an overview. For details of the frameworks and reviews we refer to the original and comprehensive literature. Our knowledge synthesis was combined with international expert panel comments and a workshop with conference participants.

The goal of this report is to provide an overview of the current knowledge of person-centred care, and to do so in a generic sense. We also critically illustrate the theoretical and empirical advancement of the field so far. In this way, the overall purpose of the initiative is to provide a benchmark to further scientific progress and possibly invite an opportunity for a more comprehensive state of science conference in the future. The objective of the conference workshops was to provide an overview of the state of person-centred care pertaining to core theoretical foundations, and modes and strategies for translating person-centred care into practice.

Outline of the report

The report gives a brief overview of major theoretical frameworks related to person-centred care. First we present the framework developed at the University of Gothenburg Centre for Person-Centred Care, the GPCC, in Sweden, for which development has been led by Dr. Inger Ekman (Chapter 2.1). This framework is explicitly founded in ethics, which is operationalised into practically applicable interventions. Next we present the 5th iteration of the person-centred practice framework developed by Drs. Brendan McCormack and Tanya McCance, primarily in the UK and in Ireland (Chapter 2.2). This framework has ‘practice’ at its core that is operationalised through all relationships involved at the point of care, developed and nurtured in person-centred care cultures. This is followed by a presentation of the person-centred care model developed by Dr. Maria J Santana in Canada (Chapter 2.3), which focuses on how to support health professionals to collaboratively promote quality care for patients, family carers and people in the communities to stay healthy. Finally, we have an overview of frameworks for integrated care and population health management by Dr. Viktoria Stein from the Netherlands (Chapter 2.4). Features of the most common integrated care frameworks are presented, along with the basis for their development and major applications.

The next chapter presents five research literature reviews, all of which are extended abstracts of original papers presented elsewhere, or work in progress. The first of these reviews the broader scope of literature on person-centred care using different terms for the concept (Forsgren and colleagues, Chapter 3.1). The second is a systematic review of cardiovascular person-centred practice (Tyagi and colleagues, Chapter 3.2). The third is a systematic review of key components for the implementation of person-centred care for older people in out-of-hospital care settings (Ebrahimi and colleagues, Chapter 3.3) and the fourth an exploration of leadership dynamics and person-centred care practices (Anker-Hansen & Femdal, Chapter 3.4). The fifth and final review is a systematic review of costs and associated health outcomes of person-centred care interventions (Pardhan and colleagues, Chapter 3.5).

The following chapter presents commentaries on the state of science in person-centred care from an international panel who participated in workshops during the GCPCC (for workshop outlines see Appendix). These start with a brief exploration of the essence of person-centred care through diverse philosophical perspectives (Chapter 4.1) and comprise comments on major concepts and features of person-centred care (Chapter 4.2) and primary strategies and principles for person-centred care knowledge translation (Chapter 4.3). Further, there are comments on prerequisites, mediators and expected outcomes for person-centred care knowledge translation (Chapter 4.4) and comments on micro-meso-macro links and interrelations for person-centred care knowledge translation (Chapter 4.5). The commentaries conclude with thoughts on practice implementation (Chapter 4.6).

In our view, the advancement in person-centred care is framed by its development in relation to broader societal trends and movements. Thus, in Chapter 5, Dr. Axel Wolf from the GPCC presents an example of this framing in regard to precision health and its integration with person-centred care.

The final chapter concludes the report with reflections by the editors on the way forward in explicating the state of the science in person-centred care (Chapter 6).

References

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

Cloninger, C. R., Salvador-Carulla, L., Kirmayer, L. J., Schwartz, M. A., Appleyard, J., Goodwin, N., Groves, J. A., Hermans, M. H. M., Mezzich, J. E., van Staden, C. W. & Rawaf, S. (2014). A Time for Action on Health Inequities: Foundations of the 2014 Geneva Declaration on Person- and People-centered Integrated Health Care for All. *International Journal of Persson-Centered Medicine*, *4*(2), 69–89.

Committee on Quality of Health Care in America. (2001). *Crossing the quality chasm: A new health system for the 21st century*. National Academies Press.

Dewing, J. (1999). Dementia. Part 1: Person-centred care. *Professional Nurse*, *14*(8), 585–8.

Feldthusen, C., Forsgren, E., Wallström, S., Andersson, V., Löfqvist, N., Sawatzky, R., Öhlén, J. & Jakobsson Ung, E. (2022). Centredness in health care: a systematic overview of reviews. *Health Expectations*, *25*(3), 885–901. https://doi.org/10.1111/hex.13461.

Gröne, O., & Garcia-Barbero, M. (2001). Integrated care: A position paper of the WHO European Office for Integrated Health Care Services. *International Journal of Integrated care*, *1*, 1–10. https://doi.org/10.5334/ijic.28.

Håkansson Eklund, J., Holmström, I. K., Kumlin, T., Kaminsky, E., Skoglund, K., Höglander, J., Sundler, A., Condén, E. & Summer Meranius, M. (2019). "Same same or different?" A review of reviews of person-centered and patient-centered care. *Patient education and counseling*, *102*(1), 3–11. https://doi.org/10.1016/j.pec.2018.08.029.

Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: Personhood and well-being. *Ageing & Society*, *12*(3), 269–287. https://doi.org/10.1017/S0144686X0000502X.

Komatsu, H. (2008). Process of developing people-centered care. *Japan Journal of Nursing Science*, *5*(2), 117–122. https://doi.org/10.1111/j.1742-7924.2008.00104.x.

Leplege, A., Gzil, F., Cammelli, M., Lefeve, C., Pachoud, B., & Ville, I. (2007). Person-centredness: Conceptual and historical perspectives. *Disability and*

Rehabilitation, *29*(20–21), 1555–1565. https://doi.org/10.1080/09638280701618661.

Nilsson, S., Björkman, B., Almqvist, A. L., Almqvist, L., Björk-Willén, P., Donohue, D., Enskär, K., Granlund, M., Huus, K. & Hvit, S. (2015). Children's voices–Differentiating a child perspective from a child's perspective. *Developmental Neurorehabilitation*, *18*(3), 162–168. https://doi.org/10.3109/17518423.2013.801529.

Richards, A. C. (1975). Toward more person-centered care. *AORN Journal*, *22*(5), 782–786. https://doi.org/10.1016/S0001-2092(07)63193-7.

Rogers, C. 1961. *On becoming a person: A therapist's view of psychotherapy*. London, Constable.

Townsend, E., Brintnell, S., & Staisey, N. (1990). Developing guidelines for client-centred occupational therapy practice. *Canadian Journal of Occupational Therapy*, *57*(2), 69–76. https://doi.org/10.1177/000841749005700205.

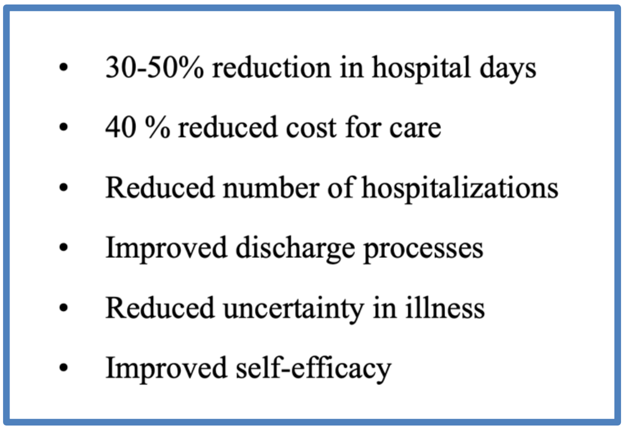
WHO, World Health Organization. (2007). *People-centred health care: a policy framework*. World Health Organization, Western Pacific Region. Retrieved 3 November 2024 http://who.int

2. Major frameworks on person-centred care

2.1 Person-entred care with a foundation in ethics

Inger Ekman

Since its inauguration in 2010, GPCC has distinguished itself with a focus on the ethics and philosophy of the patient as a person. This distinctive approach has not only been the foundation of several controlled clinical trials evaluating person-centred care, but has also yielded positive results, instilling a profound sense of optimism about the potential of person-centred care (Figure 2.1.1).



- 30-50% reduction in hospital days
- 40 % reduced cost for care
- Reduced number of hospitalizations
- Improved discharge processes
- Reduced uncertainty in illness
- Improved self-efficacy

Figure 2.1.1. Results from the evaluations of the GPCC framework on person-centred care in different healthcare settings (Britten et al, 2020)

Here I will briefly describe the ethical considerations and their relationship to the practice and research of person-centred care that have been an important source of inspiration in our work in GPCC.

The GPCC framework is founded upon the ethics of action, particularly the ethics of Paul Ricoeur, which are summarized as '*aiming for the good life, with and for others in just institutions*' (Ricoeur, 1992). This ethical framework **encompasses both individual autonomy and solicitude for others, as well as justice for all.** The autonomy of myself is about my self-esteem; each of us aims for the good life, but always together with others, always with others and directed towards others, being together in partnership. Self-esteem is correlated with the pursuit of the ethical objective of healthcare professionals, specifically the well-being and health of patients, as it represents a shared understanding and agreement about what should be accomplished. Solicitude can be seen as an umbrella term of consideration and care and explains how it unfolds the relational dimension of self-esteem. Due to their intrinsic connection, self-esteem cannot be experienced without the desire for solicitude and care towards others. In person-centred care, 'just institutions' play a pivotal role. These are the institutions where every patient can expect to be treated with the utmost respect and dignity, and all health professionals can have confidence in their organisation, knowing that it is based on fair and ethical principles. These institutions, not defined by restrictive rules but by a bond of common practices, should be seen as an extension of human relationships to all those outside the face-to-face encounter of an I and you, the anonymous other; and this emphasis on 'just institutions' underscores the ethical and respectful nature of person-centred care.

Pursuing 'the good life' in the Aristotelian tradition aims for what is good, which makes life 'flourish'. In the context of health care, the staff in each situation must imagine what can be good for each patient. This approach requires imagination and skill. Person-centred care entails healthcare professionals collaborating with patients (and often their close relatives) and, for example, developing and implementing a personalised health plan. Sometimes, the patient is very sick and helpless, which puts great demands on the staff when they try to understand how the good life can take shape for the unique patient. Person-centredness in action can be seen as a process that validates the patient's resources/abilities and desires, even in severe illness. The process involves a deep commitment to mutual respect and working together in a collaborative partnership. This ethical objective is a guiding principle to effectively attain the primary purpose, ensuring the patient's well-being.

Ricoeur states that a person's vulnerability should not be considered a problem but as a crucial part of what makes us human. We are vulnerable towards others' suffering; as health professionals, we are sensitive to a patient's suffering and take action to relieve it. This dialectical approach comprehends the capable human being as both an acting person who endures suffering and a suffering person who possesses agency. Thus, the patient is a capable partner in care and can morally hold themselves responsible for their actions.

We possess both capabilities and vulnerabilities, with the latter serving as a source of our strength. Patients can communicate, act, and be accountable for their actions. For this reason, we also integrated a capability approach developed by Amartya Sen and Martha Nussbaum, both professors in philosophy and Sen also in economics (Nussbaum, 2011; Sen, 2009). One example from their research is impoverished Indian women and micro-loans. Human capabilities can be strengthened or neglected by interaction with other human beings. This ability to empower or disempower is particularly evident in situations characterised by asymmetrical relationships, often observed in health care.

According to Ricoeur, Kantian morality is at once subordinate and complementary to Aristotelian ethics because the ethical goal needs to be critically assessed and passed through the examination of the norm. Person-centred care combines teleological and deontological perspectives and helps health care professionals formulate and plan judgments in difficult care situations. For the health professional, this can be practised by, for example, breaking the generic rules of the care setting to relieve the patient's suffering. This could involve something as simple as serving coffee to patients off schedule, or helping a patient contact someone they have difficulties reaching.

Drawing on Ricoeur's writings, Swedish philosopher Bengt Kristensson Uggla suggests there is no shorter path to the good life than moral judgment and practical wisdom in concrete situations (Kristensson Uggla, 2022). Health care is about activities and practices involving moral discernment, leading health professionals to frequently encounter substantial uncertainty. In other words, conviction and critically reflecting upon convictions are necessary elements in health care. To guarantee the systematic and consistent implementation of person-centred care (i.e. not just when we feel we have time for it), we must establish routines that effectively initiate, integrate, and safeguard this approach in daily clinical practice. For the professional to understand and assess the means to attain health and well-being for each patient, an alliance between the patient and the caregiver must be established.

A broad group of researchers from different disciplines and the European patient forum collaborated to author a consensus white paper outlining the three routines within the partnership, the GPCC framework. The approach is founded upon an explicit ethical framework that combines the relational aspects of collaboration with facilitating structures. It acknowledges the patients' needs while considering them capable and resourceful partners, with expert knowledge about their daily lives and goals. The model is framed and featured by the concept of

partnership, thereby emphasizing mutual respect and collaboration between health care professionals and patients (Ekman 2022; Ekman et al, 2011) (Figure 2.1.2).

Initiating the partnership –
patient (and relative) narratives

Developing the partnership –
mutual understading and creation of a
health plan

Safeguarding the partnership - documenting
the agreed goals and a health plan

Figure 2.1.2. Building partnership

Initiating the partnership

Skilfully engaging in active listening to the patients' narratives is a prerequisite for delivering person-centred care. The patient is always a person who can communicate their experiences, emotions and thoughts regarding their illness or situation through verbal expression, non-verbal cues and body language. Health professionals therefore need to listen to the patient's story and try to understand how symptoms such as pain or anxiety affect their everyday life. The narrative, which often develops alongside that of family carers, can, on occasion, be a coherent story. Nevertheless, stories can also emerge in a care situation on a hospital ward, during rehabilitation at a health centre, or at home.

The patient narrative, or collection of narratives, comprises the sick person's account of their illness, symptoms and its effects on their daily existence. It captures the person's suffering in an everyday context, in contrast to medical narratives that reflect the process of diagnosing and treating the disease. The patient narrative constitutes the starting point for person-centred care and lays the foundation for a partnership in care. The act of inviting someone to share their narrative conveys the significance given to the person's experiences, emotions, beliefs and preferences. A patient is a human being with dual attributes, encompassing both subjective and objective elements that represent distinct forms of reality. The subjective aspect refers to the inner world of lived experiences, while the objective aspect pertains to the outer world defined by natural sciences, including organs and genes, which predominantly govern the healthcare landscape. Biological markers or images are important data, but they serve as a complement to the patient's narrated experiences of their condition as a basis for a personal care and treatment plan. While person-centred care is founded on the subject, it still needs to incorporate elements of naturalism to ensure the provision of high-quality and professional care (Figure 2.1.3).

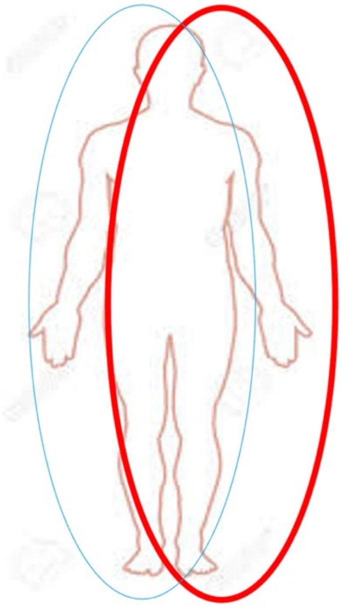


Figure 2.1.3. A person is a human being with dual attributes: subject and object, based on the assumption "Me and my body cannot be separated and still are not the same" (Ricoeur, 1966)

Working the partnership

Different conditions and diagnoses are often discussed in health care as either somatic (bodily) or psychic (emotions). A distinction is made between objective observations (e.g. blood pressure or pulse) and experiences of illness (e.g. pain), which can lead to a mechanistic view of the body and its functions (Wallström, & Ekman, 2018). Due to rapid advancements in medical technology, the precise measurement of various disease changes has become possible. Consequently, there is a growing concern that the focus on the patient's narratives during the interaction between healthcare professionals and patients may be overshadowed by the emphasis on discovering and documenting objective bodily changes.

Narrative communication involves sharing experiences and learning from each other. Telling and listening is a way of creating a common understanding of the illness experience, which, together with objective measurements of disease, gives the professional a good basis for discussing and planning care and treatment with the patient. Indeed, person-centred care starts with partnership-building and includes sharing information, deliberation, and decision-making. Despite the availability of effective and safe treatments for long-term conditions (e.g. diabetes, chronic heart failure, hypertension), many patients do not achieve the recommended target doses or optimal care. Given the progressive nature of long-term diseases and the need for extensive illness management, professionals and patients (often including relatives) must develop a partnership to achieve commonly agreed goals. Health professionals must show that they believe patients have the experiences they describe. Nevertheless, it can sometimes also be necessary to handle the patients' explanations of the experiences in a respectful way. For example, if a patient says: "I have a terrible headache; it's probably a brain tumour", the experience of having a headache cannot be questioned – on the other hand, the diagnosis of a brain tumour, the patient's interpretation, needs further investigation. For professionals to be able to discuss the significance of the experience of pain and what further examinations and tests might follow, establishing a trusting relationship with the patient is a prerequisite (Lundin et al, 2023; Lilja et al, 2024).

The task at hand involves the advanced process of listening, discussing and reaching consensus on a health plan that the patient deems feasible and significant for implementation. Assisting patients in recognising their capabilities and resources, rather than solely focusing on their needs, can prove challenging.

Safeguarding the partnership

The personal health plan involves an agreement which is preceded by a discussion or 'negotiation' that must be based on both evidence-based knowledge (mainly represented by the professionals) and experiential knowledge (represented by health professionals, patients and family carers). Thus, health professionals and patients collaboratively develop a health plan spanning one or more hours, a day or several weeks. The plan consists of collectively devised long-term and short-term strategies. Examples of potential goals could include playing golf, undertaking professional tasks, or managing anxiety or pain. Documenting the personal health plan in patient records which are accessible to both patient and professional gives legitimacy to patient perspectives, while also making the patient-professional interplay transparent and facilitating continuity in care. Registering and updating the plan and its goals must be considered just as mandatory as clinical and lab observations.

The process of implementing more person-centred care requires continuous and systematic efforts in recognising and acknowledging the importance of genuine knowledge and practice in the ethics of this field. This has implications for stakeholders and managers to facilitate and mandate the study of ethics by health professionals, just as they would for other matters, in order to deliver optimal patient care.

References

Britten, N., Ekman, I., Naldemirci, O., Javinger, M., Hedman, H., & Wolf, A. (2020). Learning from Gothenburg's model of person-centred healthcare. *BMJ, 370*, m2738. doi.org/10.1136/bmj.m2738

Ekman I. (2022). Practising the ethics of person-centred care balancing ethical conviction and moral obligations. *Nursing Philosophy, 23*(3),e12382. https://doi.org/10.1111/nup.12382

Ekman, I., Swedberg, K., Taft, C., Lindseth, A., Norberg, A., Brink, E., Carlsson, J., Dahlin-Ivanoff, S., Johansson, I. L., Kjellgren, K., Lidén, E., Öhlén, J., Olsson, L. E., Rosén, H., Rydmark, M., & Sunnerhagen, K. S. (2011). Person-centered care – ready for prime time. *European Journal of Cardiovascular Nursing, 10*(4), 248–251. doi.org/10.1016/j.ejcnurse.2011.06.008

Kristensson Uggla B. (2022). What makes us human? Exploring the significance of Ricoeur's ethical configuration of personhood between naturalism and phenomenology in health care. *Nursing Philosophy, 23*(3), e12385. https://doi.org/10.1111/nup.12385

Lilja V, Wallström, S., Saarijärvi M, Lundberg M, Segertoft VA, Ekman I. (2024). Balancing between being the most valuable player (MVP) and passing the ball: A qualitative study of support when living with chronic pain in Sweden. *BMJ Open, 14*(1), e079229. https://doi.org/10.1136/bmjopen-2023-079229

Lundin Å, Ekman I, Wallström, S., Andréll P, Lundberg M. (2023). Suffering out of sight but not out of mind - interpreting experiences of sick leave due to chronic pain in a community setting: A qualitative study. *BMJ Open, 13*(4),e066617. https://doi.org/10.1136/bmjopen-2022-066617

Nussbaum, M. (2011). *Creating capabilities: The human development approach*. The Belknap Press of Harvard University Press.

Ricoeur, P. (1966). *Freedom and nature: The volontary and the involontary*. Translated with an introduction by E.V. Kohák. (Originally published in French under the title Le Volontaire et l'involontaire, 1950.) Northwestern University Press.

Ricoeur, P. (1992). *Oneself as another* (K. Blamey, Trans.). The University of Chicago Press.

Sen, A. (2009). *The idea of justice*. Belknap Press.

Wallström, S. & Ekman, I. (2018). Person-centred care in clinical assessment. *European Journal of Cardiovascular Nursing*, 17(7), 576–579. https://doi.org/1474515118758139

2.2 Person-centred practice

Brendan McCormack

The work that I have been engaged in for 27 years or so has been underpinned by the Person-centred Practice Framework (PCPF), developed by Prof Tanya McCance and I (Figure 2.2.1), and now in its 5th iteration (McCance & McCormack 2021) in terms of refinement through the various studies that we have been doing over that period. This does not mean the framework has changed dramatically. All of the changes have been nuanced and smaller refinements, and not significant domain changes. An overview of the evolution of the PCPF can be found in McCormack (2020)

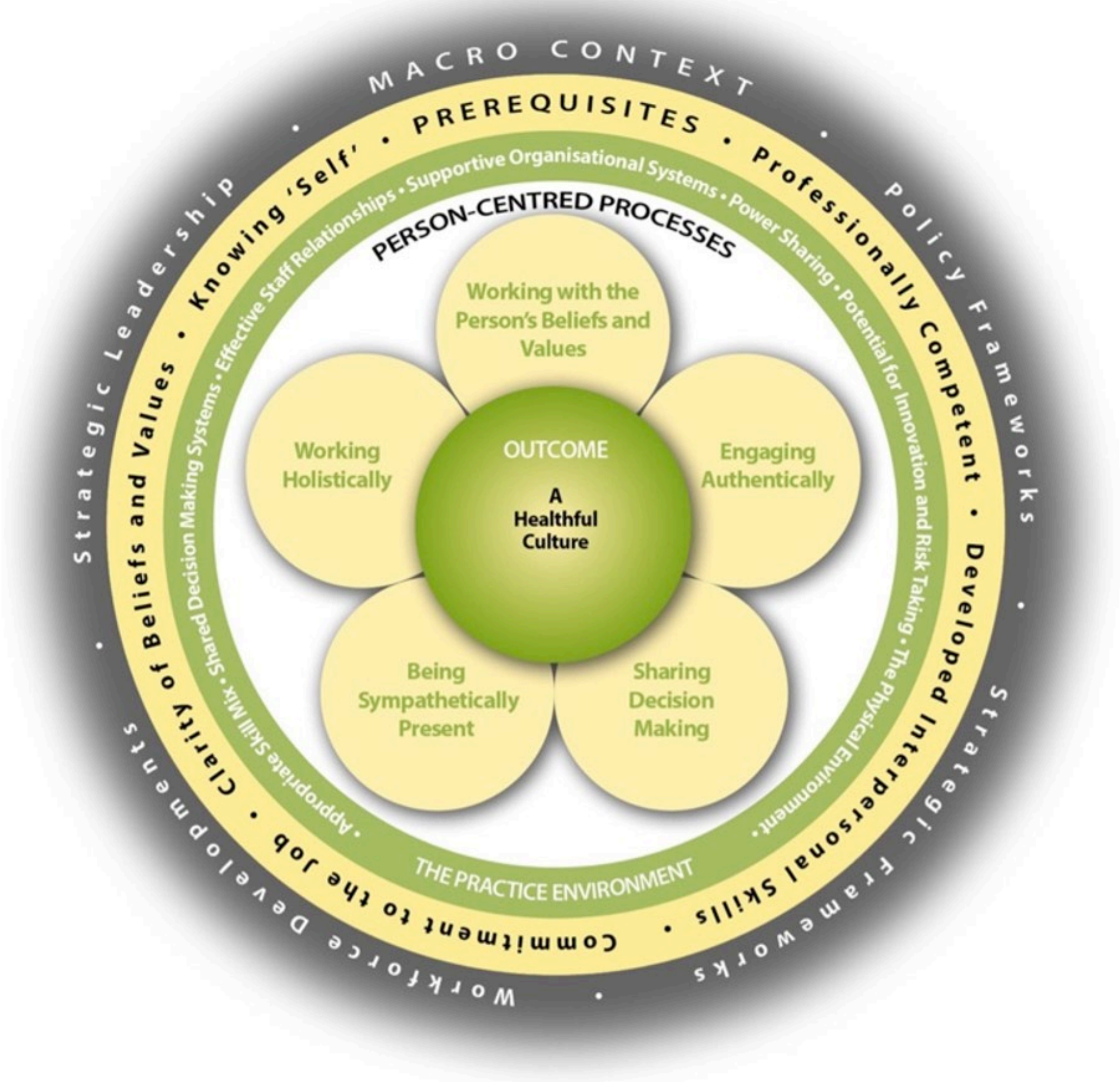


Figure 2.2.1. The Person-centred Practice Framework by McCance and McCormack (2021)

Background

The PCPF is based on original work I did in Oxford and Tanya McCance did in Ulster. When I moved to Belfast in 2000, we realized we had been working in the same area and from that, we designed the very first iteration of what became the Person-Centred practice framework. Since then, it has been used a lot in a variety of countries globally and in many different kinds of contexts and settings, as well as in a variety of practice areas. I summarised these developments of the PCPF and its impacts globally in a paper commissioned by the Royal College of Nursing UK (McCormack 2020).

From the outset, one of the core principles in the framework has been to work with the idea of person-centred practice. From a nursing perspective, person-centred care is problematic, as it implies a focus on the care that is provided in a direct 1 on 1 care relationship (individual patient, family etc). However, this does not reflect the whole system of care and the ecology of the system in which direct care is provided. So, from the outset we rejected the idea of just talking about person centred care and focused on person-centredness being a 'practice' that is operationalised through all relationships – with patients and families, with colleagues and in and between teams. We have contended that a whole-systems approach is essential for the sustainability of person-centred care, as without the same person-centred principles being applied to all persons in the system, person-centred care cultures can never be realised.

The issue of care versus practice has been problematic in this space. The first version of the PCPF was published in 2006. We were very quickly challenged in relation to what were referred to as models and frameworks of care that 'went beyond person-centred care', such as relationship-centred care. This challenge is indicative of the problem of focusing on person-centred care (seen as direct care giving) rather than on the whole-system of care and the multi-level relationships that are needed and that exist to create such a system of person-centredness.

I believe a similar situation occurred when the WHO adapted the term 'people-centred care', i.e. a misunderstanding of what the word 'person' means (i.e. the single individual person) as opposed to person meaning personhood applied at individual, group and population levels. So, from our theoretical perspective, 'practice' applies to everything that happens in a system of healthcare, that the philosophy of personhood has to be applied to the whole system, and that different practices are needed in each part of the system to reflect a person-centred philosophy that can ultimately support effective person-centred care for persons, people and populations. Our message has not gone unheard, and over the period this framework has existed, it has been translated into 14 different languages and adapted in a variety of contexts in 31 different countries. We have developed three different measuring tools for evaluating staff, patients/families and students' perspectives on person-centredness in different contexts, as well as an observation of practice tool and KPIs.

From the outset, the framework adopted a whole systems approach. Person-centred care is important in relation to the actual experience patients have, but it is also important to everyone who works to shape the services within which patients receive care. All persons are equal. Personhood is not a hierarchy. Every person's personhood matters. Hence, we have a strong focus on the personhood of healthcare workers as much as we do on the experience of patients.

Macro context

The macro context reflects the factors that are strategic and political in nature that influence the development of person-centred cultures. These factors operate regionally (within country), nationally, internationally and globally. The World Health Organization (WHO 2007), The Institute of Health Improvement People and Family-centred Care Programme and The Health Foundation (2016) have each produced strategic frameworks for developing health systems that draw on principles of integration, population health promotion and illness prevention, as well as 'people-centred' approaches to healthcare delivery. Alongside these international and global strategic frameworks, at a national level many of the principles outlined have been translated into national policies and strategies that act to guide, inform and regulate healthcare delivery – for example, it is common practice these days for professional codes of conduct to include statements and standards for person-centred care and practice, or for national strategy documents to be located within a person-centred healthcare frame of reference. Regionally, these national strategies are translated into strategic plans, strategic goals and key performance indicators of healthcare delivery organisations and their funders. Attributes of the macro context include: policy frameworks, strategic frameworks, workforce developments, and strategic leadership.

Prerequisites

The prerequisites focus on the attributes of staff and are considered to be key building blocks in the development of healthcare workers who can deliver effective person-centred care. Attributes include: being professionally competent, having developed interpersonal skills, being committed to the job, being able to demonstrate clarity of beliefs and values, and knowing self. There is no hierarchy in relation to these attributes, with all considered of equal importance, but it is the combination of attributes that reflect a person-centred individual who can manage the challenges of a constantly changing context. The last attribute of a health professional, 'commitment to the job', is probably the most controversial one because there is a risk of interpreting that you have to work harder and longer to be effective in providing person-centred care. And you do not. There is a phenomenological idea of being present while doing my work. That I am present, committed and passionate about it and that I am there. That attribute is meant to be used for people to think about the meaning of commitment when talking about this kind of work.

The practice environment

The practice environment reflects the complexity of the context in which healthcare is experienced. I can have all the best qualities, attributes and skills as a person-centred practitioner, but frankly work in a really poor environment. Then I cannot provide person-centred care because the system stops me from putting these qualities into practice. This is an issue for practitioner burnout, and the impact of the environment on practitioner health and wellbeing. The care environment is the mediator to how the system operates and what happens in relation to staff and patient experience. The position taken within the Person-centred Practice Framework is that context is synonymous with the practice environment, and contained within it are multifaceted characteristics and qualities of the environment (people, processes and structures) that impact on the effectiveness of person-centred practice. To this end, seven characteristics of the care environment are described within the framework including: appropriate skill mix; systems that facilitate shared decision making; the sharing of power; effective staff relationships; organisational systems that are supportive; potential for innovation and risk taking; and the physical environment. What is interesting about this domain is that the characteristics of the context have stayed stable really throughout this work. They have not changed in the various places, domains and countries that we have worked with. We would contend that the constructs that comprise the practice environment have a significant impact on the operationalisation of person-centred care and have the greatest potential to limit or enhance the facilitation of person-centred processes. There is multiple evidence to demonstrate the impact of context on patient care, on patient safety, on effectiveness and implementation, and on evidence uptake.

Person-centred processes

Person-centred processes focus on ways of engaging that are necessary to create connections between persons, which include: working with the person's beliefs and values; engaging authentically; being sympathetically present; sharing decision making; and working holistically. In the Person-centred Practice Framework, the person-centred processes apply to all those involved in healthcare delivery and those in receipt of care. It is important at the outset to acknowledge that the person-centred processes are synergistic and often interwoven in the delivery of healthcare. The processes are not shaped by the setting, the healthcare specialty, or where the practice takes place or who is practicing. The most controversial process in our framework is 'being sympathetically present'; note empathy is not mentioned at all. It is not that we reject empathy, instead what we are suggesting is that empathy does not go far enough and may be flawed when it comes to being person-centred because I can never be you and you can never be me. I can never understand you and you can never understand me. Being genuine about personhood, you can be alongside in that phenomenological space. You can be alongside one another, work together to understand, help and be in that space.

Outcome

The expected outcome to arise from the development of effective person-centred practice is a healthful culture. A healthful culture is one in which decision-making is shared, relationships are collaborative, leadership is transformational, and innovative practices are supported. Development of a healthful culture has the potential to create conditions that enable human flourishing for those who give care and for those who receive care. A healthful culture is energy giving – a culture helping everyone to flourish, both staff and patients, and families and communities. A place people want to be in. The challenge of creating healthful cultures is a serious one and is evidenced in the international data showing retention rates of staff across healthcare systems. I recently published a paper (McCormack, 2024) that posed the question, "Do we have a shortage of nurses? Or do we have a global shortage of places where nurses want to work?" Frankly, I think it is the latter. We need to address this as a whole system. We cannot ask practitioners to provide person-centred care if not all these elements of the whole system are addressed on a continuous basis. Hence it needs to be a continuous project.

Person-centred practice, when understood as a concept embedded in every strategy and policy, has the potential to shape health care planning and delivery. The Person-centred Practice Framework is inclusive of all persons and it clearly articulates how key components can be embedded in everyday practices at macro, mezzo and micro levels of practice, with the ultimate outcome of developing a workplace that enables human flourishing for all. However, the development and sustainability of person-centred cultures is a never-ending process, and one that needs tangible and real sustained commitment from healthcare organisations. For too long, providing person-centred care has been predominantly seen as an individual practitioner responsibility, without the same degree of overt corporate responsibility from healthcare organisations. The sustainability of person-centred care is dependent on the existence of person-centred cultures and without this it remains an elusive ideal that is fragile and transient in nature.

References

McCance, T., McCormack, B. (2020). The Person-centred Practice Framework. In B. McCormack, T. McCance, S. Martin, A. McMillan, C. Bulley (Eds.), *Fundamentals of Person-Centred Healthcare Practice.* Wiley Blackwell. https://www.perlego.com/book/2068078 (accessed on 2nd October 2024)

McCormack, B. (2020). The person-centred nursing and person-centred practice frameworks: From conceptual development to programmatic impact. *Nursing Standard – RCN Fellows Special Supplement 35*(10), 86–89. https://doi.org/10.7748/ns.35.10.86.s40

McCormack, B. (2024). The ecology of human flourishing embodying the changes we want to see in the world. *Nursing Philosophy*, *25*(3), e12482 https://doi.org/10.1111/nup.12482

The Health Foundation (2016) *Person-centred care made simple: What everyone should know about person-centred care.* The Health Foundation, London https://www.health.org.uk/sites/default/files/PersonCentredCareMadeSimple.pdf

World Health Organization (2007) People-centred Health Care: A Policy Framework. https://www.who.int/publications/i/item/9789290613176

2.3. Person-centred care in healthcare quality improvement: a conceptual framework

Maria J Santana

Person-centred Care (PCC) is a model of care in which healthcare systems professionals are encouraged to partner with patients to co-design personalized care that provides people with the high-quality of care that they value and need (Santana et al, 2018).

Healthcare systems are organizations in which people are central to its success. People in healthcare include the healthcare professionals, patients, family carers and people of our communities. The PCC model of care is about 'working together.' In a PCC model of care, healthcare professionals need to be supported to work in a PCC environment and patients, family carers, and people from our communities need to be informed about existing resources to stay healthy. This means the PCC approach is complex, context dependant and involves all the aforementioned parties to reach a perfect equilibrium amid the values, preferences, needs, duties and skills of all the participants of the healthcare system.

In the past, healthcare policies addressing the importance of and supporting the PCC model have been scant. This was due to the prominent paternalistic model of care. More recently, as the culture of healthcare has been changing, recent policies recognize the importance of PCC, making efforts to emphasize the needs, preferences and values of patients and people of our communities. Evidence shows that people value not only complementary health professional perspectives, but also those that provide unique information about healthcare effectiveness (Santana et al, 2018; NHS Department of Health, 2009), including improvement of patient experiences and outcomes, and health professional satisfaction, while decreasing healthcare services utilization and costs (McMillan et al, 2013). Based on this evidence and the need to address escalating healthcare costs, many healthcare systems around the world are moving towards a PCC model (Santana et al, 2018).

A seminal initiative from the World Health Organization (WHO) resulted in policy frameworks for people-centred health care (World Health Organization, 2007) highlighting person-centredness as a key component of healthcare quality (World Health Organization, 2006). In these policies, people-centred health care has been described as "care that is respectful and more responsive to the needs of people and strives to keep them healthy and free of illness" (World Health Organization, 2006).

Healthcare system priorities include achieving high quality of care. PCC is an important care model to consider, as it improves healthcare system efficiency and effectiveness (McMillan et al, 2013). Despite the solid evidence around the benefit of PCC, it has not traditionally been integrated into healthcare quality improvement initiatives. This gap may be due to the complexity of how to implement PCC quality improvement strategies.

This short account presents a conceptual PCC Framework (Santana et al, 2018) co-developed with patients, family carers and people of our communities. The motivation was that healthcare quality improvement has traditionally been led by surveys developed by healthcare professionals without the involvement of the patients, caregivers and people, who are the ultimate healthcare services users. This framework can be used to inform and guide healthcare systems in their efforts to improve quality from the perspective of the patients, family carers and people of our communities.

The PCC Framework (Santana et al, 2018) was developed based on evidence including a scoping review of published and unpublished papers (Santana et al, 2019; Ahmed et al 2018) on identifying existing practices nationally and internationally (Doktorchik et al, 2018) and being informed by healthcare professionals and managers, as well as patients, family carers and people of our communities (Ahmed et al, 2019; Santana et al, 2020). We also explored health policy documents available in our province and across Canada.

In addition to the academic work and involvement of patients, caregivers and people of our communities, we established a meaningful partnership with a diverse group of experts, including the team from the provincial Ministry of Health and community-based non-profit organization (Santana et al, 2018; Manalili et al, 2022). This partnership, based on common interest and PCC values, also supported the co-designing of the framework and Person-centred quality indicators (Santana et al, 2018; Manalili et al, 2022). The partnership with non-profit community organizations allowed us to include diverse people (race, ethnicity, gender, sexual identity, and socio-economic status), immigrants and refugees. With the partners we used a people-rights approach in alignment with the WHO PCC policies framework (World Health Organization, 2007). PCC is anti-discriminatory care.

We used the Donabedian's theory for quality of care that includes three domains – structure, process and outcome to evaluate quality of care – helping us to classify the PCC domains found in our searches of the literature and during consultations with people. Briefly, let me guide you through the PCC framework for healthcare quality improvement (Santana et al, 2018), see Figure 2.3.1.

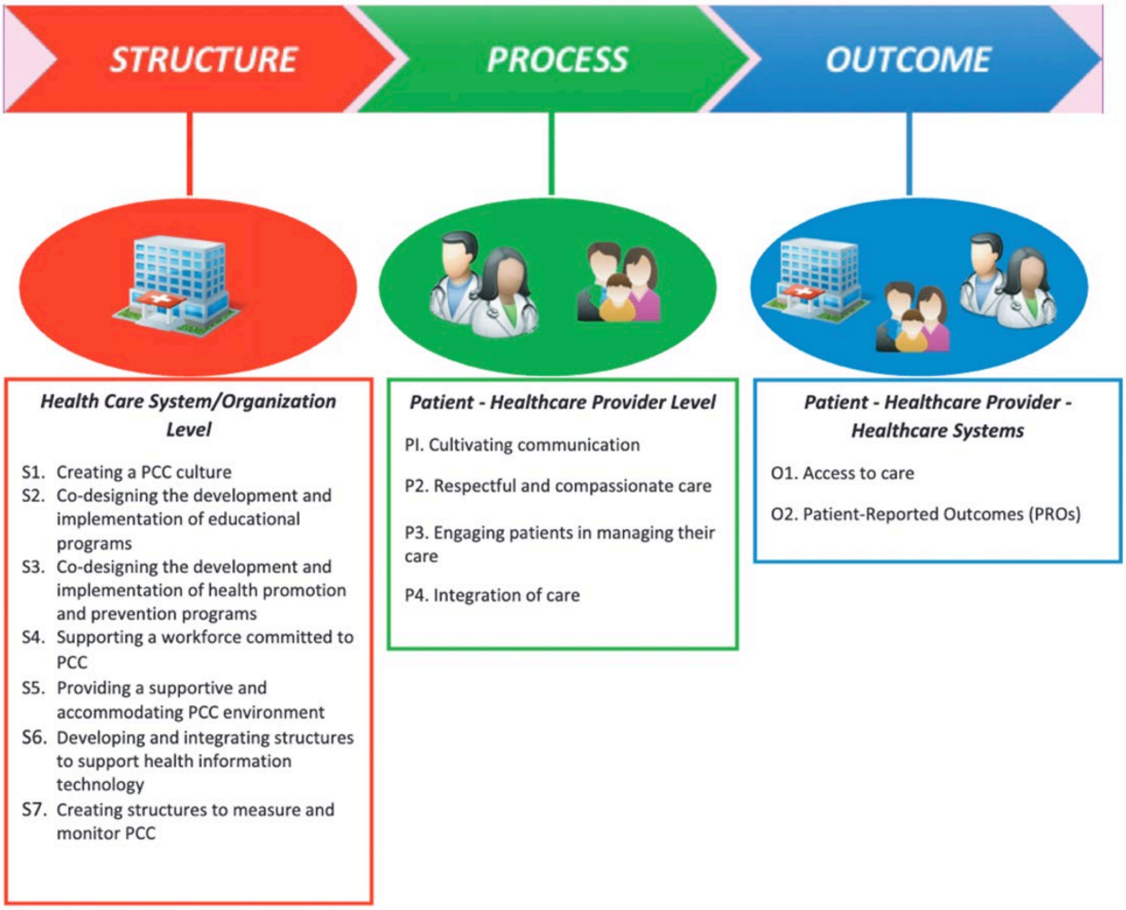


Figure 2.3.1. Framework for person-centred care (Santana et al, 2018)

The structural domain relates to the healthcare system context in which care is delivered, providing the foundation for PCC including the necessary materials, healthcare resources, and organizational characteristics. The PCC structures influence the processes and outcomes of care (Santana et al, 2018).

Structural domains include: the creation of a PCC culture across the continuum of care; co-designing educational programs, as well as health promotion and prevention programs with patients; providing a supportive and accommodating environment; and developing and integrating structures to support health information technology and to measure and monitor PCC performance (Santana et al, 2018).

Process domains relate to the quality of care associated with the interaction between patients, caregivers, people and healthcare professionals, also involving any healthcare service personnel. This domain includes a *description of the importance of cultivating communication, respectful and compassionate care; engaging patients in managing their care; and integration of care* (Santana et al, 2018).

Outcome domains aim to assess the quality of care associated with the delivery of PCC, and *include assessing access to care and Patient-Reported Outcomes* (Santana et al, 2018).

As this framework is described in Santana et al. (2020) manuscript, a brief discussion is provided, starting with the *structure domain* and highlighting some of the sub-domains, including *Creating a person-centred care culture across the continuum of care.* PCC culture may differ across settings, and culture is contextual. Despite the efforts made by healthcare systems we are not there yet. It's complex! An aspect to consider is the inclusion of the PCC model in healthcare professional education. Currently, most of the curriculum focuses on biomedical models; this is not surprising as the traditional paternalist approach to care is still prominent. There is no doubt about the urgency to develop and implement training that includes patient input, i.e. a new curriculum co-developed by healthcare professionals and patients to support the cultural shift.

Co-designing the development and implementation of health promotion and prevention strategies is especially challenging because people need to understand that they are at risk of becoming patients. People need to be supported to engage in health promotion and prevention activities. The challenges are numerous. For instance, the social determinants of health play an important role in developing promotion and prevention strategies. Understanding and addressing factors that hinder people in our communities from participating in health promotion and prevention programs is paramount. More efforts are needed to address the unaffordability of basic needs, like access to healthy food. Access to wellness programs is also difficult for many people who work shift hours and more than one job, limiting their time for exercise. The onus, therefore, is on governments to implement health and social policies to support the co-design of health promotion and prevention programs engaging with people who are at risk of chronic conditions.

Supporting the workforce PCC is a core competency of the health work force (World Health Organization, 2007). Health professionals should be supported by the healthcare organizations to practice PCC, otherwise the PCC change required at healthcare system level will never happen.

Providing a *PCC environment* starts with involving patients, caregivers and people of our communities in co-designing the environment according to what the 'PCC environment' looks like to them. Lessons can be learned from urban design, where neighbourhoods are designed with the people. The PCC environment at hospital level can be quite diverse, depending on hospital location, whether it is rurally situated or not, and the population served. A local example is the Alberta Children's Hospital that was co-designed with architects, engineers, patients and families to create a friendly and safe environment. The environment, despite being hospital-like, caters for children and includes a school, library, and an animal shelter, where families can bring their pets to visit the children. When the window cleaners come to clean the windows they come in costumes, like Batman and Spiderman, and the kids love it.

Information technology is key in supporting PCC, as it can support access to patients' information and enhances self-management while providing a sense of agency and empowerment to patients. For instance, our local electronic medical system has a patient portal that allows patients to access their own data and communicate with their healthcare providers by email. *Integration of care and care coordination* are both enhanced by the ability of patients accessing their records and being able to interact with their clinicians via the portal.

Process of care involves several domains, including *Cultivating communication*. Optimal communication aspects include actively listening to patients to collect information and discussing approaches to health, which involves mutual sharing of information between the health professional and patient in discussing care plans. The evidence generated by our team from provincial patient-reported experience surveys data and text data collected via the concerns portal showed that communication was the main driver towards overall experience with care, and was a predictor of future visits to emergency care (Kemp et al, 2022, 2024).

The PCC outcomes demonstrate the value of implementing the PCC model. Among the outcomes is the system's capacity to provide timely access to care that is cost efficient to the patient and healthcare system. Timely access to care reduces cost by preventing patients from using emergency services. Timely access to care can be seen not only as reduced waiting times (test results, referrals, surgical intervention) but also in terms of accessing health care outside regular hours. Limited access to timely care is the reality for many people due to working long hours and/or multiple jobs, or being unable to access care due to issues with language literacy, and in some cases cultural shock that prompts them to seek care in their country of origin. The complexity of assessing access to care was highlighted while we started validating these domains with the communities. Although access to care was a priority for them, financial constraints prohibited this for some services – specifically dental care, psychologists and ambulance cost (Santana et al, 2018; Manalili et al, 2022).

Patient-Reported Outcomes (PROs) are also considered PCC outcomes. The PROs included in this PCC framework are: 1) Patient-Reported Outcome Measures (PROMs); 2) Patient Reported Experience Measures (PREMs); and 3) Patient-Reported Adverse Outcomes (PRAOS). These three outcomes report what is important to patients in specific situations. Evidence revealed that using PROMs during the patient-health professional consultation is challenging (Bele et al, 2023) and Healthcare systems barriers prevent the adoption of PROMs as standard clinical practice (McCabe et al, 2023). Moreover, in Canada and many other countries, PREMs are collected routinely at healthcare system level, and data derived from PREMs can inform quality improvement that is based on patient experiences (Kemp et al, 2022, 2024).

This conceptual framework has been beneficial not only in guiding local quality improvement initiatives but also international PCC work. For example, at national level, the PCC framework has informed the development of person-centred quality indicators (Santana et al, 2020), a project supported by the Canadian Institutes of Health Research, the Canadian Institute for Health Information and the provincial health quality council. These indicators are now being implemented in primary care across the province to continue the efforts to integrate a PCC healthcare system. Additionally, at international level, the PCC Framework has informed the work of others. An example is the PCC work done by Giusti et al. (2022). This work highlights and addresses the gap of PCC initiatives in low and middle-income countries. The authors have adapted Santana's framework to this specific context while highlighting the need for international PCC efforts in a quest to gather global data.

To move forward with a PCC model, more efforts are needed from all parties – patients, caregivers, people of our communities, organizations and health systems leaders – in working together towards equitable care that support our values, preferences and needs. The onus is on all of us.

References

Ahmed, S., Djurkovic, A., Manalili, K., Sahota, B., Santana, M. J. (2019). A qualitative study on measuring patient-centered care: Perspectives from clinician-scientists and quality improvement experts. *Health Science Reports. 2*(12), e140. https://doi.org/10.1002/hsr2.140.

Ahmed, S., Siad, F. M., Manalili, K., Lorenzetti, D. L., Barbosa, T., Lantion, V., Lu, M., Quan, H., Santana, M. J. (2018). How to measure cultural competence when evaluating patient-centred care: A scoping review. *BMJ Open, 8*, e021525. https://doi.org/10.1136/bmjopen-2018-021525

Bele, S., Rabi, S., Zhang, M., Ahmed, S., Oddone Paolucci, E., Johnson, D. W, Quan, H., Santana, M. J. (2023). Uptake of pediatric patient-reported outcome and experience measures and challenges associated with their implementation in Alberta: A mixed-methods study. *BMC Pediatrics 23*, 369 https://doi.org/10.1186/s12887-023-04169-w

Doktorchik, C., Manalili, K., Jolley, R., Gibbons, E., Lu, M., Quan, H., Santana, M. J. (2018). Identifying Canadian patient-centred care measurement practices and quality indicators: A survey. *CMAJ Open, 6*(4), E643-E650. https://doi.org/10.9778/cmajo.20170143

Giusti, A., Pukrittayakamee, P., Alarja, G., et al. (2022). Developing a global practice-based framework of person-centred care from primary data: A cross-national qualitative study with patients, caregivers and healthcare professionals. *BMJ Global Health, 7*, e008843. https://doi/10.1136/bmjgh-2022-008843

Kemp, K. A., Fairie, P., Steele, B., Santana, M. J. (2022). How to analyze and link patient experience surveys with administrative data to drive health service improvement. *International Journal of Population Data Science. 7*(4). https://doi.org/10.23889/IJPDS.V7I4.1763.

Kemp, K., Steele, B., Ahmed, S., Fairie, P., Santana, M. (2024). Person-centred quality indicators are associated with unplanned care use following hospital discharge. *BMJ Open Quality, 13*, e002501. https://doi.org/10.1136/bmjoq-2023-002501.

Manalili, K., Siad, F. M., Antonio, M., Lashewicz, B., Santana, M. J. (2022). Codesigning person-centred quality indicators with diverse communities: A qualitative patient engagement study. *Health Expectations, 25*(5), 2188–2202. https://doi.org/10.1111/hex.13388

McCabe, E., Rabi, S., Bele, S., Zwicker, J. D., Santana, M. J. (2023). Factors affecting implementation of patient-reported outcome and experience measures in a pediatric health system. *Journal of Patient-Reported Outcomes. 7*(24) https://doi.org/10.1186/s41687-023-00563-1

McMillan, S. S., Kendall, E., Sav, A., et al. (2013). Patient-centered approaches to health care: A systematic review of randomized controlled trials. *Medical Care Research and Review, 70*, 567–596. https://doi.org/10.1177/1077558713496318.

NHS Department of Health. (2009). *NHS 2010-2015: From Good to Great. Preventative, people-centred, productive.* https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/228885/7775.pdf (accessed on 2nd October 2024).

Santana, M. J., Ahmed, S., Lorenzetti, D. L., Jolley, R. J., Manalili, K., Zelinsky, S., Quan, H., Lu, M. (2019). Measuring patient-centred system performance: A scoping review of patient-centred care quality indicators. *BMJ Open, 1*, e023596. https://doi.org/10.1136/bmjopen-2018-023596

Santana, M. J., Manalili, K, Jolley, R. J., Zelinsky, S., Quan, H., Lu, M. (2018). How to practice person-centred care: A conceptual framework. *Health Expectations. 21*(2),429–40. https://doi.org/10.1111/hex.12640.

Santana, M. J., Manalilli, K., Zelinsky, S., Brien, S., Gibbons, E., King, J., Frank, L., Wallström, S., Fairie, P., Leeb, K., Quan, H., Sawatzky, R. (2020) Improving the quality of person-centred healthcare from the patient perspective: Development of person-centred quality indicators. *BMJ Open, 10*(10), e037323. https://doi/10.1136/bmjopen-2020-037323

World Health Organization. (2006). *Quality of care : a process for making strategic choices in health systems*. World Health Organization. https://iris.who.int/handle/10665/43470 (accessed on 2nd October 2024).

World Health Organization. (2007). *People-centred health care: A policy framework*. WHO Regional Office for the Western Pacific. https://iris.who.int/handle/10665/206971 (accessed on 2nd October 2024).

2.4 Frameworks for integrated care and population health management implementation

Viktoria Stein

Over the years, many frameworks have been developed for integrated care, spurred on by research programmes on a national and European level. This has led to the development of frameworks for integrated care in specific settings (e.g. primary care, such as the Rainbow model of Integrated Care; Valentijn 2016; Valentijn et al., 2015) or for specific diseases (e.g. dementia and stroke care, the Development Model for Integrated Care; Minkman, 2012). Even though no comprehensive analysis and comparison of the many frameworks has been conducted so far, the development for most frameworks started with a systematic literature review; and as the literature base is usually very similar, the content of most frameworks is comparable as well. Good examples of frameworks building on previous literature are the Project INTEGRATE framework, the WHO global framework for integrated people-centred health systems and the WHO European Framework for Action on integrated health services delivery. All published around the same time, the main difference lies in how they cluster and arrange the main elements or building blocks of integrated care. It is impossible to give a satisfactory overview of the frameworks, so I will introduce a few well-known and often-cited ones.

One of the oldest frameworks on integrated care is Ed Wagner's Chronic Care Model (CCM), first published in 1998. It was never intended to be a framework, but it has been applied worldwide, and first summarised the main elements from a system's perspective of what was needed to build an integrated, primary care led health system. The Scirocco model, first developed for the European Innovation Partnership on Active and Healthy Ageing (EIP-AHA), is still used across the European Union and is an assessment tool for systems to look at their maturity of integration, visualise the perceptions of different stakeholders and facilitate cross-sector, interdisciplinary priority setting towards more integrated care (https://www.sciroccoexchange.com/).

The following will further describe three frameworks which I have helped develop. The first is the WHO European Framework for Action on Integrated Health Services Delivery (WHO EFFA IHSD), which was developed by WHO Europe through input and consultations with its 53 member states: an invited group of experts and different European umbrella organisations, for example, the European Patient Forum and Eurordis. Interestingly, even though this is a policy framework, it also has the ambition to foster implementation, and thus primarily targets ministries of health and national public health institutions. Building on other WHO frameworks, it describes three pillars which need to be addressed: Populations and Individuals, Services Delivery Processes, and System Enablers (Figure 2.4.1). Uniquely, it also defines 'Change Management' as a separate and supporting block to be addressed. The lack of investment in change management knowledge and people is still being identified in the literature and practice as one of the biggest barriers to successful and sustainable change, so featuring this prominently in the framework is a major strength.

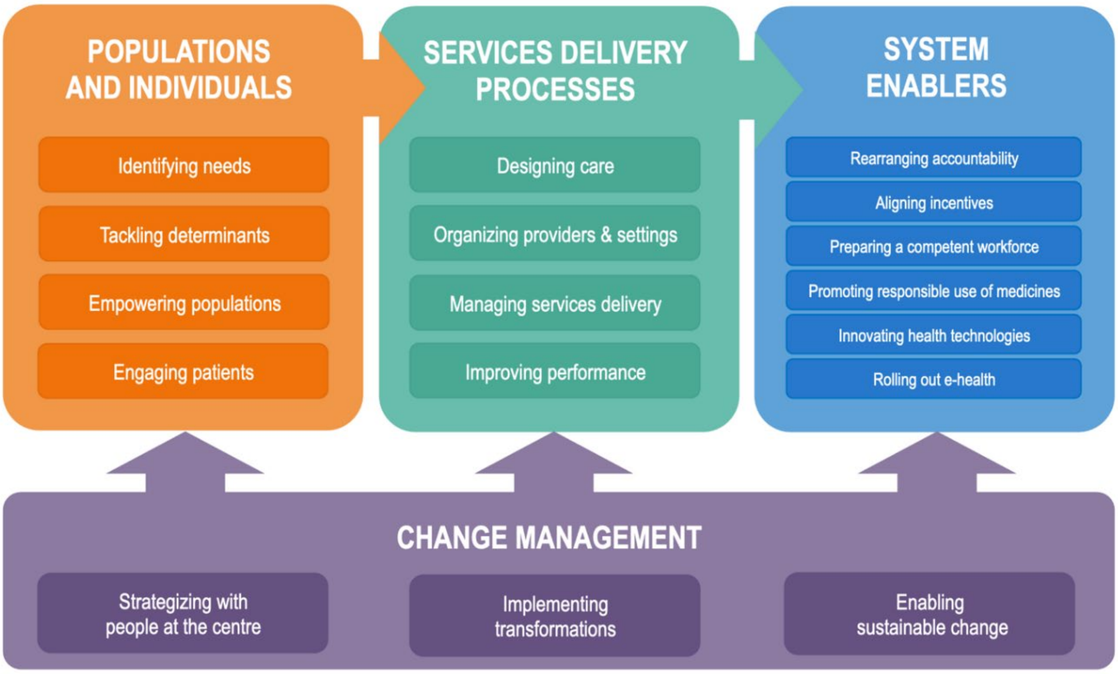


Figure 2.4.1. The European Framework for Action on Integrated Health Services Delivery (WHO, 2016, p. 3, CC BY-NC-SA 3.0 IGO)

On the WHO Europe website, there are a number of documents available to support implementation, such as a toolkit and several case studies: https://who-sandbox.squiz.cloud/en/health-topics/Health-systems/health-services-delivery/european-framework-for-action-on-integrated-health-services-delivery-effa-ihsd.

The second is the aforementioned Project INTEGRATE framework, which was developed as part of an EU research project. Here the target audience was more on a regional or local level, addressing public administrators and managers tasked with implementing integrated care, often based on national policies or strategies. The main questions were: how can we support managers in implementing integrated care? The Project INTEGRATE framework refined the initial items identified as important from the literature by testing and discussing them together with four case sites. It was based on the idea that integration needs to happen on all levels of the system, and that the activities and topics depended on which level of the system you were working on. Two levels, normative and functional integration, were cross-cutting topics which had to be addressed on all levels (Figure 2.4.2). These included, for example, culture and values, education or language (normative) or IT, communication, technology and data sharing (functional).

Although first intended as a planning tool with the intention of addressing all levels equally, it became clear through the piloting workshops with the case sites that the framework was a lot more useful as a basis for discussing the status quo of integrated care with representatives from one level, highlighting different perspectives and perceptions and facilitating priority setting. However, the framework also helps managers to define which elements are either not currently relevant or cannot be influenced by them. As such, it is designed as an assessment tool: 'Do we have the same impression of where we are? Are there priorities that we need to look at?

Figure 2.4.2. The Project INTEGRATE framework (Calciolari et al, 2022)

With the case sites we found that this is really an implementation and continuous learning tool to support those discussions and decision making on the different levels. It also highlighted that you cannot discuss or plan for all seven levels of integration with everyone, because for people working on the ground it is sometimes very abstract to talk about policy making. The framework helps break down and organise the complexity of integrated care implementation and focus stakeholders and implementers on what they can and cannot do. For this reason, considering which audience is using the framework is key in supporting integrated care implementation.

Finally, the Population Health Management Maturity Index (Figure 2.4.3) was developed by one of our LUMC PhD students over the last three years in the Netherlands. Again based on a scoping review and a Delphi study, this index has been used by one of the local health districts in Australia to test whether it is transferable outside the Dutch context. Presented over the years at various scientific conferences, it fits in with a general move towards population health management as a data-driven and more holistic approach to person-centred care. Our research team are discussing with Ontario Health Teams, the Welsh government and Ireland about possible applications in their endeavours to strengthen and expand their efforts towards more integrated, person-centred care. The Dutch Ministry of Health will use the index as an implementation tool for their current policies on integrated person-centred care, which requires regional networks to come together and develop population health management initiatives. The added value of the PHM-MI is that it was conceptualised from the outset as a tool to support the development of a learning health system, answering the question 'What do we need to do when?'. Thus, it is trying to bring together the step-by-step approach of change management with the continuous learning cycles and uncertainties of implementing change in a complex system.

Breaking down complexity by prioritising what needs to be done now, as opposed to in one or two years, facilitates the change management process by focussing on manageable steps rather than looking at the need for change in the whole system.

In summary, there are many frameworks to choose from. Do not develop your own. Take one and adapt it. Choose the one that fits your context, setting and audience. Because there is no one right framework. All these frameworks recognise that you need to intervene on different levels of the system. Using the WHO frameworks will usually facilitate system level changes.

Figure 2.4.3. The Population Health Management Maturity Index (van Ede et al, 2023)

If the focus is on the management or the professional level, then there are other more useful frameworks. All integrated care frameworks emphasise community involvement, co-design and stakeholder involvement from the very beginning. So if you truly want to implement integrated, person-centred care, involve people from day one, and ask them, what is it that we want to do together? And by people, I mean both the population and communities you are working in, and the workforce, which needs to change their way of working. If you do not use co-design methods, it will come back to haunt you. It is one of the main reasons why projects fail and why we are still discussing fragmented systems after decades of developing person-centred models and frameworks to overcome them. Co-design is essential in implementation, but again it needs to be well planned, targeted and meaningful. However, this is a whole different discussion.

Note that any framework is a guide, a starting point to come together and discuss what to focus on, what to prioritise, what can be influenced and what cannot. This is not a tick box exercise. Think through how to measure, how to improve, how to feedback and how to involve your partners. Ultimately, a framework is a tool to create a learning environment and a learning organisation.

References

Berwick, D. M. Reflections on the chronic care model – 23 years later. (2019). *Milbank Quarterly*, *97*(3), 665–668. https://doi.org/10.1111/1468-0009.12414

Calciolari, S., González, Ortiz. L., Goodwin, N., Stein, V. (2022). Validation of a conceptual framework aimed to standardize and compare care integration initiatives: the project INTEGRATE framework. *Journal of Interprofessional Care*, *36*(1), 152-160. https://doi.org/10.1080/13561820.2020.1864307

Minkman, M. M. N. (2012). Developing integrated care. Towards a development model for integrated care. *International Journal of Integrated Care*, *12*(12),e197. https://www.sciroccoexchange.com/resources. https://doi.org/10.5334/ijic.1060.

National Voices and TLAP. (2013). *A narrative for person centred coordinated Care.* National Voices. https://www.nationalvoices.org.uk/publications/our-publications/narrative-person-centred-coordinated-care (accessed on 2nd October 2024)

Valentijn, P. P. (2016). Rainbow of chaos: A study into the theory and practice of integrated primary care. *International Journal of Integrated Care*, *16*(2),3. https://doi.org/10.5334/ijic.2465

Valentijn, P. et al. (2015). Towards an international taxonomy of integrated primary care: a Delphi consensus approach. *BMC Family Practice*, *16*(1),64–015-0278-x. https://doi.org/10.1186/s12875-015-0278-x.

van Ede, A. F. T. M., Minderhout, R. N., Stein, K. V., Bruijnzeels, M. A. (2023). How to successfully implement population health management: a scoping review. *BMC Health Services Research*, *23*, 910. doi.org/10.1186/s12913-023-09915-5

van Ede, A. F. T. M., Stein, K. V. & Bruijnzeels, M. A. (2024). Assembling a population health management maturity index using a Delphi method. *BMC Health Services Research*, *24*,(110). doi.org/10.1186/s12913-024-10572-5

Wagner E. H. (1998) Chronic disease management: what will it take to improve care for chronic illness? *Effective Clinical Practice*, *1*(1), 2–4. https://access.portico.org/stable?au=phwwtrq3nv

World Health Organization. (2015). *People-centred and integrated health services: An overview of the evidence: interim report*. World Health Organization. https://iris.who.int/handle/10665/155004

World Health Organization. Regional Office for Europe. (2016). *The European Framework for Action on Integrated Health Services Delivery: an overview*. World Health Organization. Regional Office for Europe. https://iris.who.int/handle/10665/372341

3. Current reviews on person-centred care

3.1 Person-centred care as an evolving field of research: a scoping review

Emma Forsgren, Caroline Feldthusen, Sara Wallström, Lovisa Thunström, Lars Kullman, Richard Sawatzky & Joakim Öhlén

Looking at the research literature on person-centred care (PCC), a variety of terms are used, for example, patient-, person-, family-, woman-, or people-centred care. Several studies point to the similarity between concepts – that there are common themes – and that the use of the term/concept is more related to the setting and participants (Hughes et al, 2008; Sturgiss et al, 2022). Others discuss differences, such as the difference in the end goal of care between, for example, patient- and person-centred care concepts (Håkansson Eklund et al, 2019).

There is a large amount of research available within as well as bordering the field (for example, literature on shared decision making, or patient and public involvement). In terms of recent reviews (Sturgiss et al, 2022; Nolte & Anell, 2020; Nkhoma et al, 2022; Berntsen et al, 2022) there is also minimal overlap in the included studies, indicating a risk of presenting fragmented segments rather than a comprehensive view of the research field.

The objective of this review is to present an overview of international literature on PCC. The research questions were: (1) What populations, settings, research approaches, and designs are represented in PCC literature, 2) Which terms and keywords are used in PCC literature, and (3) Can research collaborations and clusters be observed in the research field of PCC?

The databases PubMed, Scopus, PsychINFO, CINAHL and Web of Science was searched using adapted search strings including a variety of terms. Language was restricted to English, but there was no time restriction.

To be included in the review the citations needed to (a) include PCC as a concept, independent of a specific term used in the main aim or focus, and (b) include an elaborated discussion on the concept. In this study, PCC was broadly defined in line with the GPCC model as care in which the patient's will, needs and desires are elicited and acknowledged and in which a collaborative partnership involves working with the patient, health professionals and other people of importance in the patient's life.

A combined manual and computer-assisted screening was used for stepwise identification of relevant citations. This meant we began by screening a random sample of approximately 5 000 publications from our initial data set of 94 000 publications. This screening was used to build a classifier model which ranked all remaining citations on their likelihood of being relevant. We completed a couple of rounds of screening and refined the model, but the ranking was not very precise, so we decided to change to a classifier model in an available software called EPPI-Reviewer (Thomas et al, 2023). We completed additional rounds of screening the citations ranked as most likely to be relevant and did two complimentary database searches. The screening process finally resulted in 1 351 included publications. Further details of our method can be found in Forsgren et al. (2023).

Data relevant to answering the research questions were extracted from NVivo and a complimentary bibliometric analysis was conducted to explore research collaborations.

The results show that there has been a steady increase in the literature since the 1970s until today, with an increase in publication rate at the beginning of the 21st century. Empirical and theoretical studies dominated the sample (Figure 3.1.1) and have been published at a similar speed until about 2010. Thereafter, empirical studies have dominated in terms of number of publications per year. Within the empirical studies, the dominant setting was hospital care, followed by residential/home care and primary care (Figure 3.1.2). The study population was most often health professionals or patients.

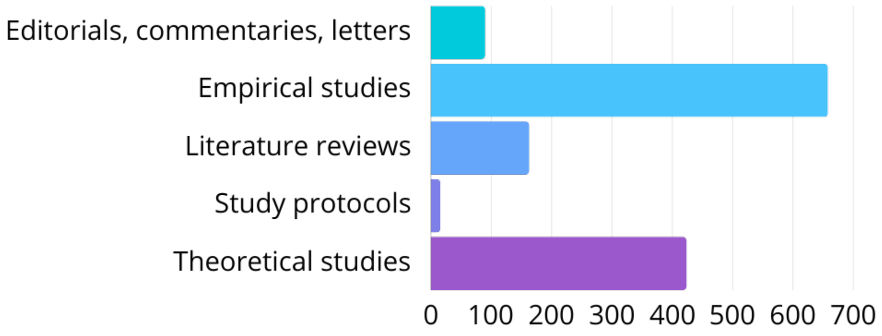


Figure 3.1.1. Reference types

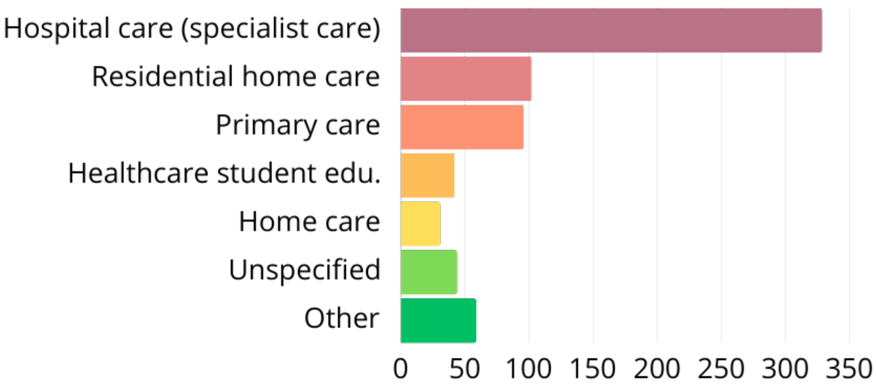


Figure 3.1.2. Settings of empirical studies

Publications on PCC use a variety of terms. In our sample, the most frequent were ‘patient-centred’, ‘person-centred’ or ‘family-centred’ care (Figure 3.1.3). The term ‘person-centred’ care is the most used term in recent years.

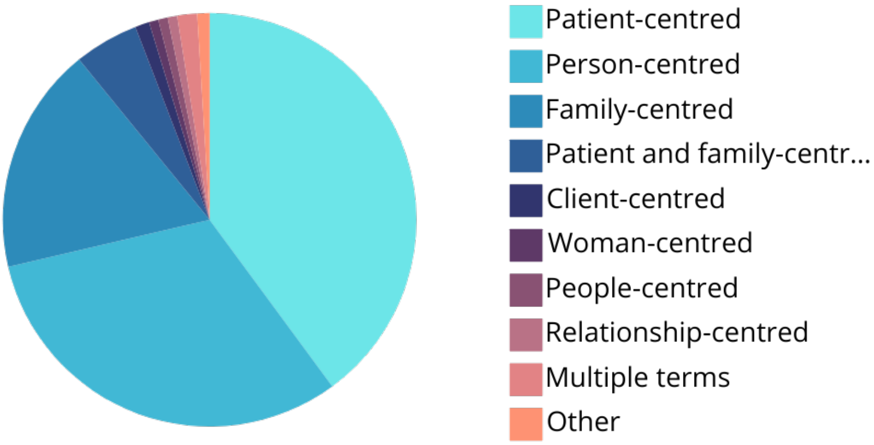


Figure 3.1.3. Terms used

PCC research is conducted worldwide across six continents and 56 countries, the top five countries being the US, UK, Australia, Canada and Sweden. There are many collaborations between researchers/universities. Relating our review to the PCC frameworks presented in Chapter 3, our results provide a broad overview of the available literature on PCC. However, there are challenges in presenting a complete and comprehensive overview due to the lack of clarity in terminology, as well as the large amount of research available. Our review shows that literature using a variety of PCC terms can be eligible for inclusion in a review of PCC. This fact has significance for further theoretical development of PCC, as it presents barriers to collating the available evidence, which in turn can hinder research-based policy and practice development.

References

Berntsen, G. C. M., Ako-Egbe, L., Yaron, S., Phan Thanh, P., Castro, I., et al. (2022). *Person-centred care systems: from theory to practice. A White paper for ISQUA.* International Society for Quality in Health Care.

Forsgren, E., Wallström, S., Feldthusen, C., Zechner, N., Sawatzky, R., Öhlén, J. (2023). The use of text-mining software to facilitate screening of literature on centredness in health care. *Systematic Reviews*, *12*(1),73. https://doi.org/10.1186/s13643-023-02242-0.

Håkansson Eklund, J., Holmström, I. K., Kumlin, T., Kaminsky, E., Skoglund, K., Höglander, J., et al. (2019). "Same same or different?" A review of reviews of person-centered and patient-centered care. *Patient Education & Counseling*, *102*(1),3–11. https://doi.org/10.1016/j.pec.2018.08.029.

Hughes, J. C., Bamford, C., May, C. (2008). Types of centredness in health care: Themes and concepts. *Medicine, Health Care and Philosophy*, *11*(4),455–63. https://doi.org/10.1007/s11019-008-9131-5.

Nkhoma, K. B., Cook, A., Giusti, A., Farrant, L., Petrus, R., Petersen, I., et al. (2022). A systematic review of impact of person-centred interventions for serious physical illness in terms of outcomes and costs. *BMJ Open*, *12*(7), e054386. https://doi.org/10.1136/bmjopen-2021-054386.

Nolte, E. & Anell, A. (2020). Person-centred health systems: strategies, drivers and impacts. In: Nolte, E., Merkur, S., Anell, A., editors. *Achieving Person-Centred Health Systems: Evidence, Strategies and Challenges* (41–74). European Observatory on Health Systems and Policies. Cambridge University Press. https://doi.org/10.1017/9781108855464.006.

Sturgiss, E. A, Peart, A., Richard, L., Ball, L., Hunik, L., Chai, T. L., et al. (2022). Who is at the centre of what? A scoping review of the conceptualisation of 'centredness' in healthcare. *BMJ Open*, *12*(5),e059400. https://doi.org/10.1136/bmjopen-2021-059400.

Thomas, J., Graziosi, S., Brunton, J., Ghouze, Z., O'Driscoll, P., Bond, M., et al. (2023). *EPPI-Reviewer: advanced software for systematic reviews, maps and evidence* *synthesis*. EPPI Centre, UCL Social Research Institute, University College London.

3.2 State of science in cardiovascular person-centred practice: a systematic review

Vaibhav Tyagi,[2] Dion Candelaria,[2] Robyn Gallagher, Jeroen Hendriks & Brendan McCormack

The authors explore the current state of person-centred practice (PCP) in cardiovascular (CV) care, challenging existing norms and proposing future directions. This work emphasizes the need for holistic approaches to CV care that encompass patients overall needs, values, preferences, and the socio-political and cultural context of their lives.

Defining person-centred practice

PCP in healthcare is a holistic approach that considers patients' needs, abilities, values and preferences that place the personhood of all persons engaged in the care experience as central to decision-making. This approach promotes equality among all participants in the care continuum and acknowledges the broader context of care delivery.

Cardiovascular person-centred care

Cardiovascular diseases (CVD) are the leading cause of death globally. However, economic and healthcare development has significantly improved survival rates for CVD patients, especially in countries like Sweden, United Kingdom and Australia (Figure 1). With advances in cardiovascular disease management and therapeutics, more people now live longer with CVD and multiple other chronic conditions. Although there is a growing consensus that person-centred care is important, evidence highlighted in Figure 3.2.1 demonstrates the need for the development of healthcare systems policies and practices that fully embrace a holistic person-centred care approach.

Models of person-centred cardiovascular practice

The American Heart Association (AHA) released a scientific statement that presents a scoping review of current person-centred models for cardiovascular

---

[2] Vaibhav Tyagi and Dion Candelaria are co-first authors.

care (Rossi et al, 2023). Their findings highlight that there is variability in methodological approaches, outcome measures, and care processes, which likely contributes to slow adoption of PCP. Identified PCP models are based on stated use of evidence-based guidelines, clinical decision support tools, systematic evaluation processes, and inclusion of patient perspectives.

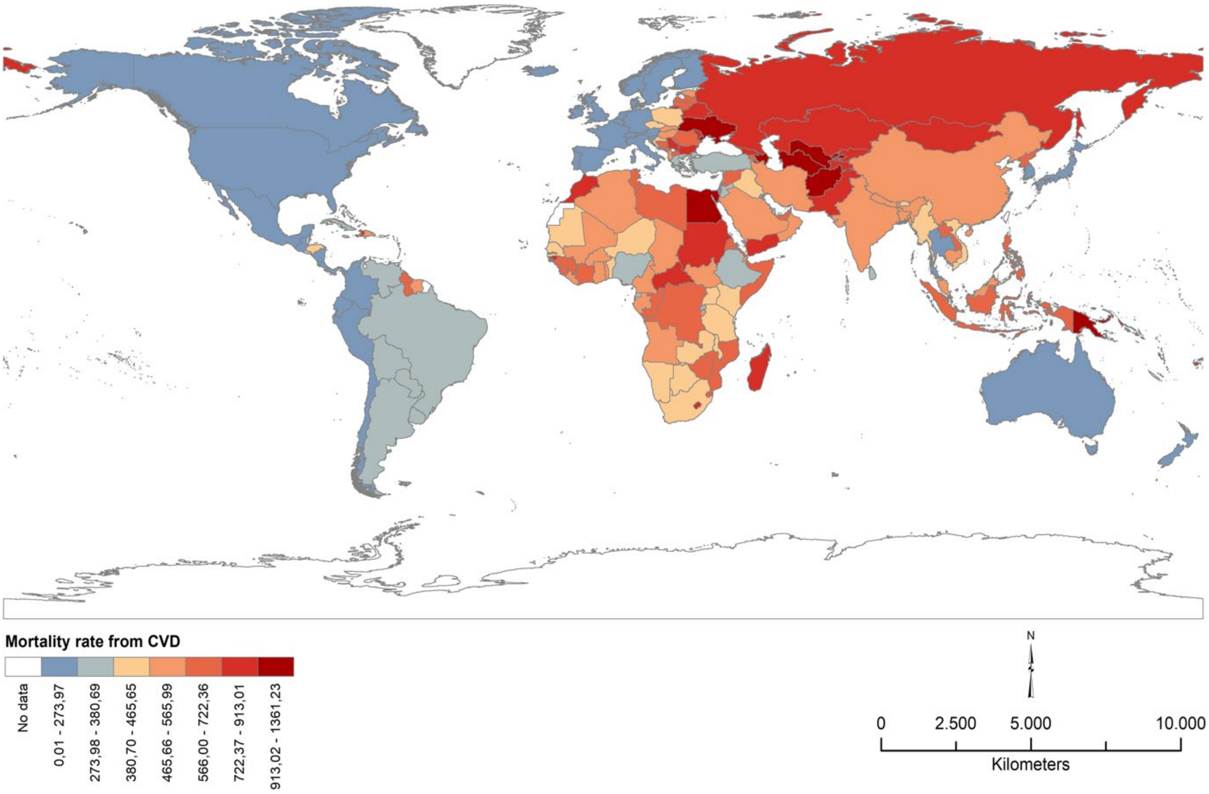


Figure 3.2.1. Age-standardized crude mortality rate from cardiovascular disease (per 100,000) by countries – 2013-2017. Reproduced from Baptista & Queiroz (2022, CC-BY).

Patient-centred vs. person-centred practice

Whilst models of patient care have evolved over time and discrete differences between patient-centredness and person-centredness have sometimes become eroded in established delivery models, patient-centred care is, by definition, a clinician-led model of care. Although patient-centred care may often include perspectives from families, extended caregivers and the patient's significant others, processes and outcomes are mediated through the clinician's professional lens.

Person-centred care models extend the potential of shared decision-making and are predicated on the basis that 'everyone is as important as everyone else', i.e. there is no hierarchy of person. This is a critical consideration, as in a person-centred approach, the person is not defined by their illness/condition (they are not cases), rather they are first and foremost persons with hopes, dreams and desires, and are full partners in their care and have an equal voice. To enable this, health professionals need to embody these person-centred values and beliefs as equal persons. For that to happen, PCP needs to be sustained through a flourishing environment for all persons in the care experience, treating everyone equally and fostering shared decision-making, leading to healthful outcomes for all.

Implementing person-centred cardiovascular care

Existing guidelines in cardiovascular care emphasize two key concepts – shared decision-making and patient involvement. For instance, The European Society of Cardiology recommends optimization of shared decision-making and patient involvement; the AHA suggests co-designing health plans with patients; and advocacy groups like the British Heart Foundation support informed, personalized decision-making. Ekman and colleagues (2021) proposed three routines for integrating PCP: initiating partnerships by listening to patients' narratives, implementing partnerships through co-created health plans, and safeguarding partnerships by documenting agreed plans. The Gothenburg model, which incorporates these processes, has been successfully implemented in clinical trials (Ekman et al, 2021). The team at Sydney Nursing School argue that it is now time to go beyond shared decision-making and patient inclusion and consider other important concepts, such as Clarity of beliefs and values, Having sympathetic presence and Knowing self.

The Person-Centred Practice Framework (PCPF) identifies shared decision-making as just one aspect of PCP (Figure 3.2.2). Future research should map current cardiovascular nursing practices against other PCP constructs, identifying gaps and areas for improvement. This includes fostering environments conducive to PCP, understanding necessary practitioner attributes, and developing person-centred processes. The PCPF also highlights that person-centred care is situated within the wider socio-political 'Macro domain'. This understanding acknowledges the important role played by time, culture, and linguistic, social and political factors in cardiovascular care.

Implications for person-centred healthcare practice

To advance knowledge in the field of person-centred cardiovascular care it is crucial to: (i) develop a clear understanding of PCP within the cardiovascular context, (ii) extend patient-centred models to encompass person-centred concepts,

(iii) go beyond shared decision-making to include all persons in the care process, (iv) recognize the need for specific clinician skill sets to facilitate PCP, and (v) acknowledge and develop the broader context in which person-centred care is provided. Models like the PCPF can provide a valuable template for adapting and evolving cardiovascular PCP.

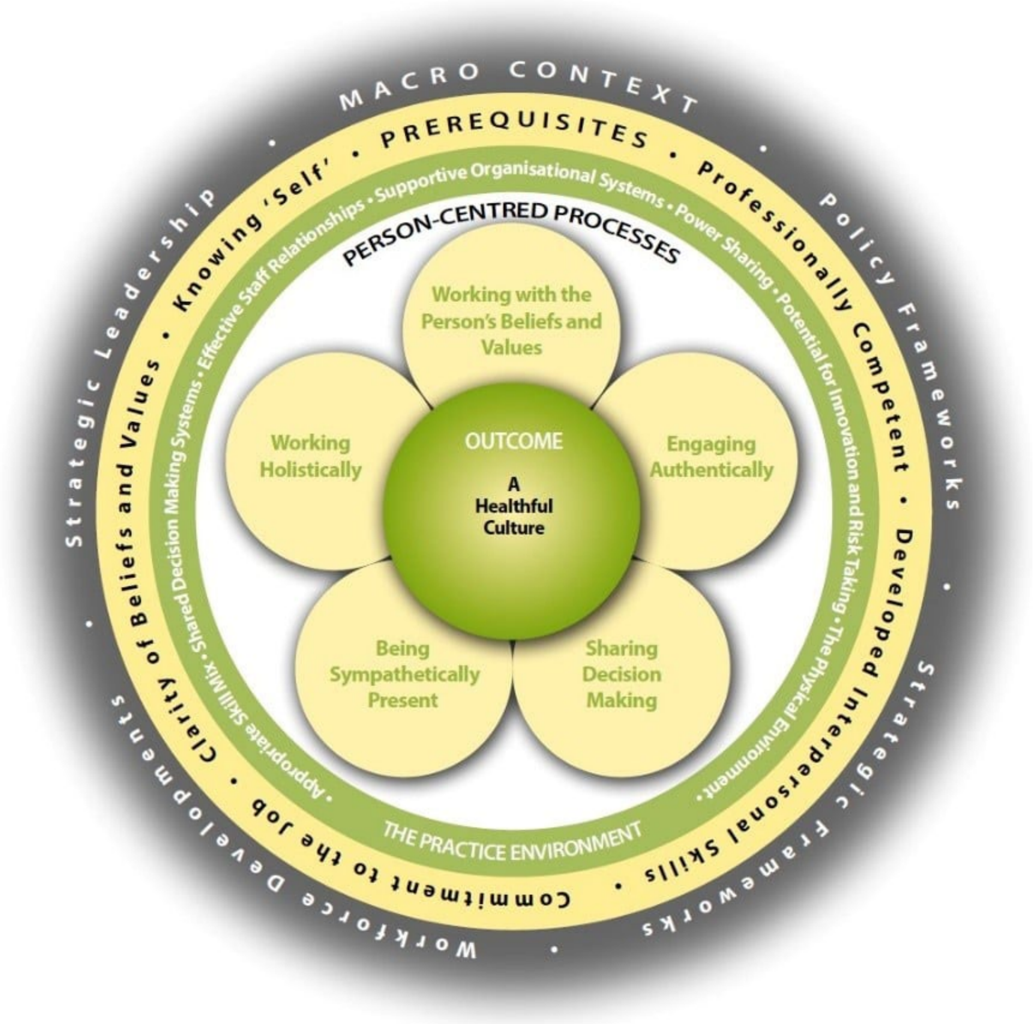


Figure 3.2.2. The Person-centred practice framework (McCormack and McCance, 2017)

Current research highlights the need for continued research and development to fully integrate PCP into cardiovascular care, ensuring that all individuals involved in the care continuum are treated as equal partners. This approach can potentially improve patient outcomes, satisfaction, and overall quality of care. An important step in this direction is a systematic assessment of existing knowledge and identification of key areas where further improvement is much needed.

References

Baptista, E. A., & Queiroz, B. L. (2022). Spatial analysis of cardiovascular mortality and associated factors around the world. *BMC Public Health, 22*(1), 1556. https://doi.org/10.1186/s12889-022-13955-7

Rossi, L. P., Granger, B. B., Bruckel, J. T., Crabbe, D. L., Graven, L. J., Newlin, K. S., ... & American Heart Association. (2023). Person-Centered Models for Cardiovascular Care: A Review of the Evidence: A Scientific Statement From the American Heart Association. *Circulation, 148*(6), 512-542. https://doi.org/10.1161/CIR.0000000000001141.

Ekman, I., Ebrahimi, Z., & Olaya Contreras, P. (2021). Person-centred care: looking back, looking forward. *European Journal of Cardiovascular Nursing, 20*(2), 93-95. https://doi.org/10.1093/eurjcn/zvaa025.

McCormack, B. and McCance, T. (2017). *Person-centred Nursing and Healthcare: Theory and Practice* (2nd Ed.). Wiley-Blackwell.

3.3 Key components in implementation of person-centred care for older people in out-of-hospital settings [3]

Zahra Ebrahimi, Harshida Patel, Helle Wijk, Inger Ekman & Patricia Olaya-Contreras

As the global population ages, the demand for healthcare services for older people outside of hospital has grown significantly (World Health Organisation, 2018; Swedish Association of Local Authorities and Regions, 2021). Healthcare systems worldwide are facing many challenges in planning and co-creation of such feasible, high-quality and cost-effective care for older people (Brodsky et al, 2002). Person-centred care can be an approach to meeting these aims (Britten et al, 2020; Olsson et al, 2013). There is no doubt about the multidimensional benefits of approaching person-centred care within healthcare systems, but there is a lack of consensus regarding the key components for translation of person-centred care into practice (Britten et al, 2020; The American Geriatrics Society Expert Panel on Person-Centered Care; Ekman et al, 2011; Glasdam et al, 2013; McCormack, 2004; McCormack et al, 2011; McCormack & McCance, 2006, 2010; Rahman et al, 2012).

Some of the descriptions being using across different health systems and settings include: “patient-centered care” in the USA (Mead & Bower, 2000), “understanding the patient as a unique human being” in the UK (Institute of Medicine Committee on Quality of Health Care in America, 2001; Balint, 1969), “partnership with the person” in Sweden (Ekman et al, 2011), “personally tailored activities” in care of people with dementia (Mohler et al, 2018), and “people-centered care” by WHO (World Health Organisation, 2013). “Patient-centered medicine” (Balint, 1969), which is more commonly associated with the acute and hospital setting (Edvardsson & Innes, 2010), “patient (and family)-centered care”; “relationship-centered care”; and “personalized care planning” (Coulter et al, 2015). “Client-centered care” (Mead & Bower, 2000; Institute of Medicine Committee on Quality of Health Care in America, 2001; Brookman et al, 2011)

---

[3] This paper is an extended abstract of a systematic review previously published: Ebrahimi, Z., Patel H, Wijk H, Ekman I &Olaya-Contreras P. (2020). A systematic review on implementation of person-centered care interventions for older people in out-of-hospital settings. *Geriatric Nursing, 8*, 1-12.

and “person-directed care” are considered in long-term care policies and guidelines in a number of countries in Europe and in North America (Edvardsson et al, 2016; Scales et al, 2019). In addition, regarding the use of different interventions in different combinations (e.g. patient-clinician communication, shared decision-making, or self-management support), another limitation and hurdle in PCC interventions is the inability to combine the results of varied interventions, surveys and outcome measures across studies (Coulter et al, 2015; Rathert et al, 2013). However, there are a plenty of terminologies, definitions and interpretations of PCC and no consensus regarding the key components for delivering such care.

Ricœur’s ethic as a theoretical framework for this review

We used the concept ‘PCC’ as an umbrella term to cover the different terms of person. To gain a deeper understanding of person-centredness we have also drawn on the work of Paul Ricœur, who describes a person as beyond the one-sidedness of “either or”, and rather as a complex, intertwined and united “ipse” (who) and “idem” (what) (Ricoeur, 1994). Ricœur is one philosopher advocating “dialogical thinking”, which aims to redefine the science by building a bridge between the two worlds of science (culture and nature). The University of Gothenburg University Centre for Person-Centred Care (GPCC) has developed a framework (Britten et al, 2020; Ekman et al, 2011; see also Chapter 2.1) rooted in the ethics of Paul Ricœur, namely “aiming at the ‘good life’ with and for others, in just institutions” (Ricoeur, 1994, p.172) as an action ethic in practising PCC (Ekman, 2022; Ekman et al, 2021).

Objective

The aim of this systematic review was to explore the content and essential components of implemented person-centred care in the out-of-hospital context for people aged 65 and older.

Research questions:

1. What is the content/mode of PCC in care for older people implemented in the out-of-hospital setting?
2. What components are crucial in person-centred care in the out-of-hospital setting?

Method

A systematic review was conducted and reported according to the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) guidelines. Searches for international published research in electronic databases PubMed, Cinahl, Scopus, PsycInfo, Web of Sciences and Embase were conducted between 2017 and 2019. Original empirical studies with intervention and/or implementation of PCC regarding older people (65+) from different countries and out-of hospital settings were included and assessed according to the quality assessment tools EPHPP and CASP. A total of sixty-three original studies from diverse countries and settings, with qualitative, quantitative and mixed methods were included and analysed using deductive thematic analysis (Clarke & Braun, 2017).

Results

An overview of the identified components of implemented PCC was described in the published review (1, in Table 3). The results showed five key components in implementation of person-centred care with and for older persons in out-of-hospital settings (Figure 3.3.1).

The syntheses of the results underscored four interconnected themes crucial to the implementation of person-centred care based on Ricœur's philosophy action ethic:

- Recognizing and validating the patient as a whole person
- Co-creating a tailored health plan
- Engaging in teamwork across various healthcare professionals and fostering cooperation with both the older persons and their relatives
- Establishing a person-centred base with focus on preventive and health-promoting actions

Comments and Conclusion

The review provides a holistic overview of the current state of person-centred care interventions for older people in out-of-hospital settings. It encompasses various healthcare settings, including primary care, home care, long-term care, and community-based services. This comprehensive systematic review highlights the crucial components of person-centred care and will hopefully contribute to achieving consensus about person-centred care based on Ricœur's philosophy and ethics of "aiming at the good life with and for others, in just institutions" (Ricoeur, 1994, p.172). Awareness and practice of this action ethical basis of PCC facilitates the planning and implementation of flexible and sustainable goals for partnership and co-creation. Approaching an interpersonal and inter-professional teamwork and consultation with a focus on risk preventive and health promotive actions is a crucial prerequisite for co-creation of optimal healthcare practice with and for older people and their relatives in their unique context, and this aligns with the goals of ongoing global reform, Integrated Care for Older People (ICOPE) and in Sweden, "Integrated and Person-centred Care" (Nära vård) (World Health Organisation, 2018; Swedish Association of Local Authorities and Regions, 2021). However, we underscore the need for continued research, policy development and practice innovation to promote the adoption of person-centred care as a standard approach for planning and co-creation of healthcare with and for older people in diverse healthcare settings.

Figure 3.3.1: An overview of the key components of person-centred care (PCC) implementation with and for older persons

References

Balint, E. (1969). The possibilities of patient-centered medicine. *Journal of the Royal College of General Practitioners*, *17*(82), 269–76.

Brodsky, J., Habib, J., Hirschfeld, M., & Siegel, B. (2002). Care of the frail elderly in developed and developing countries: the experience and the challenges. *Aging Clinical and Experimental Research*, *14*(4), 279-86. doi: 10.1007/BF03324451

Britten, N., Ekman, I., Naldemirci, Ö., Javinger, M., Hedman, H., Wolf, A. (2020). Learning from Gothenburg model of person-centred healthcare. *BMJ*, *370,* m2738. https://doi.org/10.1136/bmj.m2738

Brookman, C., Jakob, L., DeCicco, J., & Bender, D. (2011). *Client-Centred Care in the Canadian Home and Community Sector: A Review of Key Concepts*. Saint Elizabeth.

Clarke, V. & Braun V. (2017). Thematic analysis. *The Journal of Positive Psychology*, *12*(3), 297–298. https://doi.org/10.1080/17439760.2016.1262613

Coulter, A., Entwistle, V. A., Eccles, A., Ryan, S., Shepperd, S., & Perera, R. (2015). Personalised care planning for adults with chronic or long-term health conditions. *Cochrane Database of Systematic Reviews*, (3). https://doi.org/10.1002/14651858.CD010523.pub2

Ebrahimi, Z., Patel, H., Wijk, H., Ekman, I., Olaya-Contreras, P. (2020). A systematic review on implementation of person-centered care interventions for older people in out-of-hospital settings. *Geriatric Nursing*,. *8*, 1-12. https://doi.org/10.1016/j.gerinurse.2020.08.004

Edvardsson, D. & Innes, A. (2010). Measuring Person-centered Care: A Critical Comparative Review of Published Tools. *Gerontologist*, *50*(6), 834–46. https://doi.org/10.1093/geront/gnq047

Ekman, I. (2022). Practising the ethics of person-centred care balancing ethical conviction and moral obligations. *Nursing Philosophy*, *23*(3), e12382. https://doi.org/10.1111/nup.12382

Ekman, I., Ebrahimi, Z., Olaya Contreras, P (2021). Person-centred care: Looking back, looking forward. *European Journal of Cardiovascular Nursing*, *20*(2), 93-95. https://doi.org/10.1093/eurjcn/zvaa025

Ekman, I., Swedberg, K., Taft, C., Lindseth, A., Norberg, A., Bergbom, I., Brink, E., Carlsson, J., Johansson, I.-L., Kjellgren, K., Lidén, E., Öhlén, J., Olsson, L.-E., Rosen, H., Rydmark, M. & Stibrant Sunnerhagen, K., for the University of

Gothenburg Centre for Person-Centred Care (GPCC). 2011). Person-centered care – Ready for prime time. *European Journal of Cardiovascular Nursing*, *10*, 248-251. https://doi.org/10.1016/j.ejcnurse.2011.06.008

Edvardsson, D., Backman, A., Bergland, Å., Björk, S., Bölenius, K., Kirkevold, M., Lindkvist, M., Lood, Q., Lämås, K., Lövheim, H., Sandman, P.O., Sjögren, K., Sköldunger, A., Wimo, A. & Winblad, B. (2016). The Umeå ageing and health research programme (U-Age): Exploring person-centred care and health-promoting living conditions for an ageing population. *Nordic Journal of Nursing Research*, *36*(3), 168–174. https://doi.org/10.1177/2057158516645705

Glasdam, S., Henriksen, N., Kjær, L., & Praestegaard, J. (2013). Client involvement in home care practice: a relational sociological perspective. *Nursing Inquiry*, *20*(4), 329-40. https://doi.org/10.1111/nin.12016

Institute of Medicine Committee on Quality of Health Care in America (2001). *Crossing the Quality Chasm: A New Health System for the 21st Century*. National Academy Press.

McCormack, B. (2004). Person-centredness in gerontological nursing: An overview of the literature. *Journal of Clinical Nursing*, *13*(3a), 31-8. https://doi.org/10.1111/j.1365-2702.2004.00924.x

McCormack, B., Dewing, J., & McCance, T. (2011). Developing person-centred care: Addressing contextual challenges through practice development. *Online Journal of Issues in Nursing*, *16*(2), 3. https://doi.org/10.3912/OJIN.Vol16No02Man03

McCormack, B. & McCance, T. V. (2006). Development of a framework for person-centred nursing. *Journal of Advanced Nursing*, *56*(5), 472–9. https://doi.org/10.1111/j.1365-2648.2006.04042.x

McCormack, B. & McCance, T. (2010) *Person-centred Nursing: Theory and Practice*. Wiley.

Mead, N. & Bower, P. (2000) Patient-centredness: a conceptual framework and review of the empirical literature. *Social Science & Medicine*, *51*(7), 1087–110. https://doi.org/10.1016/S0277-9536(00)00098-8

Möhler, R., Renom, A., Renom, H., & Meyer, G. (2018) Personally tailored activities for improving psychosocial outcomes for people with dementia in long-term care. *Cochrane Database of Systematic Reviews*, *2*, Cd009812. https://doi.org/10.1002/14651858.CD009812.pub2

Olsson, L. E., Jakobsson Ung, E., Swedberg, K., & Ekman, I. (2013). Efficacy of person-centred care as an intervention in controlled trials – a systematic review. *Journal of Clinical Nursing*, *22*(3-4), 456-65. https://doi.org/10.1111/jocn.12039

Rahman, A. N., Applebaum, R. A., Schnelle, J. F., & Simmons, S. F. (2012). Translating research into practice in nursing homes: Can we close the gap? *The Gerontologist*, *52*(5), 597–606. https://doi.org/10.1093/geront/gnr157

Rathert, C., M. D. Wyrwich, and S.A. Boren (2013). Patient-centered care and outcomes: A systematic review of the literature. *Medical Care Research and Review*, *70*(4), 351–79. https://doi.org/10.1177/1077558712465774

Ricoeur, P. (1994). *Oneself as another*. University of Chicago Press.

Swedish Association of Local Authorities and Regions (2021). *Development of integrated care with a focus on primary care* (Utveckling av den nära vården med fokus på primärvården). Swedish Association of Local Authorities and Regions.

Scales, K., Lepore, M., Anderson, R. A., McConnell, E. S., Song, Y., Kang, B., Porter, K., Thach, T. & Corazzini, K. N. (2019). Person-Directed Care Planning in Nursing Homes: Resident, Family, and Staff Perspectives. *Journal of Applied Gerontology, 38*(2),183–206. https://doi.org/10.1177/0733464817732519

The American Geriatrics Society Expert Panel on Person-Centered Care (2016). Person-Centered Care: A Definition and Essential Elements. *Journal of the American Geriatrics Society*, *64*(1),15-18. https://doi.org/10.1111/jgs.13866

World health Organisation. (2013) *People-centred health care: A policy framework*. WHO Regional Office for the Western Pacific. https://www.who.int/publications/i/item/9789290613176 (accessed on 2nd October 2024).

World Health Organisation. (2018). *Integrated care for older people (ICOPE) implementation framework: guidance for systems and services*. World Health Organisation. https://apps.who.int/iris/bitstream/handle/10665/325669/9789241515993-eng.pdf (accessed on 2nd October 2024).

3.4 Deepening the exploration of leadership dynamics and person-centred practices: integrating the person-centred practice framework

Camilla Anker-Hansen & Ingrid Femdal [4]

Implementing a person-centred approach in nursing homes is crucial for enhancing patient satisfaction, perceived care quality, and health professional job satisfaction. Leaders are central in establishing and nurturing a culture that consistently integrates person-centred practices, benefiting both residents and staff. However, while there is a growing body of empirical evidence supporting the benefits of person-centred practice, there remains a significant gap in understanding the nuanced ways in which leaders can effectively cultivate, sustain, and adapt these practices within the complex and often resource-constrained environment of nursing homes. This gap highlights the need for more targeted research and practical strategies to guide leadership in fostering truly person-centred cultures.

Aim

This study seeks to investigate the leadership dynamics that facilitate the adoption and maintenance of person-centred practice in nursing homes, incorporating perspectives from both leadership and staff to provide a holistic understanding. In this extended abstract, we also provide commentary on how the review results align with the person-centred practice framework proposed by McCormack and McCance (see also Chapter 2.2).

---

[4] Acknowledgement of the contributions by Drs. Vigdis Abrahamsen Grøndahl, PhD, Professor, and Ann Karin Helgesen, PhD, Professor, both from the Faculty of Health, Welfare and Organisation, Østfold University College, Fredrikstad, Norway, and Dr. Carina Bååth, PhD, Professor, from the Faculty of Health, Welfare and Organisation, Østfold University College, Fredrikstad, Norway, and the Faculty of Health, Science and Technology, Karlstad University, Sweden.

Methods

A systematic review was conducted using the Joanna Briggs Institute (JBI) meta-aggregative approach, known for its rigorous synthesis of qualitative and quantitative research. Comprehensive searches were performed in CINAHL and PubMed, with article screening and selection facilitated by Rayyan software. Articles were rigorously assessed based on predefined inclusion criteria, including the relevance to leadership in person-centred practice, resulting in the inclusion of nine studies in the final analysis (five qualitative and four quantitative).

Results

The analysis revealed three core themes: visionary leadership and empowerment, a consistent and systematic approach to achieving person-centred outcomes, and leadership through role modelling. Leaders who are characterized by their ability to articulate and embody a collective vision for person-centred practice were identified as essential to fostering these practices. The importance of a structured approach to realizing person-centred outcomes was emphasized, along with the key role of leaders in embodying person-centred values through their actions.

The findings underscore the high expectations placed on leaders to facilitate the adoption and maintenance of person-centred practice in nursing homes. This study also introduces a critical perspective on the reciprocal nature of person-centredness, questioning whether staff demonstrate the same level of empathy and support for their leaders that they expect from them. This question delves into the essence of leadership dynamics and the intricate balance between expectations and support. Moreover, it raises the issue of whether traditional leadership models, often rooted in hierarchy, are sufficient in the context of modern healthcare demands. Person-centredness emphasizes the worth and dignity of every individual, including leaders, and this mutual respect is fundamental to sustaining a truly person-centred culture.

Integration with McCormack and McCance's person-centred practice framework

Our findings align closely with the person-centred practice framework proposed by McCormack and McCance (2017), which emphasizes four key constructs: prerequisites, the practice environment, person-centred processes, and outcomes. The themes identified in our review resonate with these constructs. Visionary leadership and empowerment correspond with the ‘prerequisites’ and ‘care environment’ constructs, highlighting the need for leaders who are professionally competent, committed, and capable of fostering supportive environments. This involves cultivating a culture of compassion and commitment while ensuring that the organizational setting supports person-centred practices, such as effective staff relationships and appropriate skill mix.

Leadership through role modelling fits within the ‘person-centred processes’ construct, illustrating how leaders can shape and guide the care environment by promoting values such as authentic engagement and holistic approaches to care among their staff. By demonstrating these values in their interactions and decision-making, leaders influence the processes by which care is delivered, ensuring that person-centred principles are embedded throughout the organisation.

A consistent approach to achieving person-centred outcomes aligns with the ‘outcomes’ construct, emphasising the importance of structured practices that leaders support and which lead to positive care experiences, involvement in care, and overall well-being for staff and patients. This approach underscores how effective leadership can enhance patient and staff satisfaction and contribute to the successful realisation and sustainability of person-centred practice.

Conclusions

This systematic review emphasises the crucial importance of leadership in nurturing and maintaining person-centred practices in nursing homes. Successful leadership entails developing and articulating a shared vision, empowering staff members, and implementing consistent and structured strategies. Additionally, the review points out that leaders need to embody person-centred values and receive support within a person-centred framework themselves. This mutual support is vital for establishing and sustaining a robust and enduring person-centred culture in nursing homes.

Acknowledging and addressing the difficulties encountered by leaders is essential for maintaining person-centred practices. Such a reciprocal approach, where leaders and staff both practise and receive person-centred care, is critical for cultivating a resilient and sustainable person-centred culture. By valuing and respecting the humanity of both leaders and staff and ensuring mutual support and accountability, nursing homes can create environments that enhance the quality of care and satisfaction for everyone involved. These insights provide valuable guidance for nursing home leaders and policymakers aiming to enhance person-centred practice and foster a more effective and compassionate healthcare environment.

The findings in this review align with McCormack and McCance's (2017) Person-centred Practice Framework, which emphasizes the importance of prerequisites, a supportive care environment and intentional person-centred processes in order to achieve person-centred outcomes.

Reference

McCormack, B. & McCance, T. (2017). *Person-Centred Practice in Nursing and Health Care: Theory and Practice.* Wiley-Blackwell.

3.5 Costs and associated health outcomes of person-centered interventions: a systematic review

Salma Pardhan, Hadeel Elhassan, Rasika Hewage, Benjamin Harvey & Hanna Gyllensten

Person-Centered Care (PCC) has often been linked to patient empowerment with economic benefits and better health outcomes. However, this assertion remains inconclusive when exploring individual cost-effectiveness studies pertaining to PCC, partially due to the lack of standardization in defining PCC, for which a myriad of definitions currently exists. PCC studies also tend to focus on certain age groups or ailments, further contributing to the ambiguity surrounding the cost-effectiveness of PCC.

Objective

The purpose of this study was to explore the current evidence on costs and associated health outcomes of PCC, and to examine the populations, settings, and definitions used through a systematic literature review.

Method

This systematic review [5] was conducted by two independent reviewers in accordance with the PRISMA recommendations (Page et al, 2021) using MeSH terms and free text related to centeredness (patient and people-centered care, client-centeredness, patient engagement, patient activation, and patient involvement), cost, and health outcomes. The search was conducted in 2022 in PubMed, Scopus, and CINAHL databases, and grey literature was also systematically explored. Only peer reviewed interventional, prospective, and retrospective studies reporting original cost information and using at least one of the three defining tenets of partnership outlined by the University of Gothenburg Centre for Person-centred Care (GPCC)(Britten et al, 2020; Ekman et al, 2011; see also Chapter 2.1) were included: 1) initiating partnership, 2) working the partnership, and 3) safeguarding the partnership. No restrictions on country,

---

[5] Prospero Registration # CRD42022313047.

language, or publication date were applied. The CHEC checklist (Evers et al, 2005) was used to assess the risk of bias, and the authors strove to handle data from included studies in an ethical manner.

All included papers were assessed against the GPCC model, where the degree of deviation from this model was analyzed. Papers reporting QALYs as effectiveness measures were further categorized into the four quadrants of a cost-effectiveness plane, where PCC was identified as being either:

i) cost-effective (dominant),
ii) cost-saving with negative health outcomes,
iii) more costly but effective, or
iv) more costly and less effective than usual care (dominated)

Costs were converted to a common currency and year to aid comparisons. Due to heterogeneity in the data, a meta-analysis was not feasible.

Preliminary results

Only 32 of the 2 766 papers identified in the 2022 search met the inclusion criteria. All included studies were predominantly random control trials or quasi-experimental designs conducted in high income countries: Sweden (28%), UK (19%), USA (16%), Netherlands (13%), Canada (13%), Australia (6%), Singapore (3%), and Finland (3%).

In terms of cost-effectiveness, most studies found PCC to be more cost-effective, cost-saving, or potentially cost-saving (78%, n=25) than care as usual. From the 32 papers, 19 unique studies reported QALYs and incremental cost outcomes. Most of these studies showed PCC to be both cost-saving and more effective (dominant) than care as usual. Other measures of effectiveness were reported by another 10 papers, most of which showed PCC to be dominant as well.

Caution must still be exercised when considering these findings, as it cannot be conclusively claimed that PCC is cost-effective due to several intrinsic issues with the included papers. Firstly, most of the included papers had very short time horizons, whereby only 37.5% of the studies were conducted over a 12-month horizon. Secondly, most studies showed minimal to insignificant effects on QALY measures and low clinical significance. Moreover, the included studies showed a gap in representation, as the studies predominantly focused on elderly participants over the age of 65 with chronic conditions relating to cardiac, cancer, arthritis, or mental health care. Thirdly, the chasm in understanding true cost-effectiveness of

PCC has widened due to the studies' inconsistent nomenclature, operationalization, and assessment of PCC, whereby PCC alone was assessed in various ways, including questionnaires, subjective observations or judgements by health professionals, and interactive interviews. Lastly, although there were only a handful, it cannot be ignored that some included studies found PCC to be both costlier and less effective (dominated) than usual care.

Conclusion

This study is the first to systematically explore and analyze the costs and benefits of PCC compared to care as usual using a well-established and accepted definition of PCC. Although this study confirms that PCC is cost-effective, many potential areas of bias have been identified. Future research in this area ought to explore different age groups, geography, sociocultural and socioeconomic contexts, care settings, and expand the scope beyond chronic conditions. Furthermore, more effort needs to be made to standardize the definition of PCC, and studies conducted in this area should consider a wider time horizon when assessing the long-term impact of PCC on the population. An updated database search is now in progress to identify more recent publications to further explore questions about costs and associated health outcomes of person-centered interventions.

References

Britten, N., Ekman, I., Naldemirci, Ö., Javinger, M., Hedman, H. & Wolf, A. (2020). Learning from Gothenburg model of person centred healthcare. *BMJ*, 370, m2738. https://doi.org/10.1136/bmj.m2738.

Ekman, I., Swedberg, K., Taft, C., Lindseth, A., Norberg, A., Bergbom, I., Brink, E., Carlsson, J., Johansson, I.-L., Kjellgren, K., Lidén, E., Öhlén, J., Olsson, L.-E., Rosen, H., Rydmark, M. & Stibrant Sunnerhagen, K., for the University of Gothenburg Centre for Person-Centred Care (GPCC). 2011). Person-centered care – Ready for prime time. *European Journal of Cardiovascular Nursing*, *10*, 248-251.

Evers, S., Goossens, M., de Vet, H., van Tulder, M. & Ament, A. (2005). Criteria list for assessment of methodological quality of economic evaluations: Consensus on Health Economic Criteria. *International Journal of Technology Assessment in Health Care*, *21*(2), 240–5. https://doi.org/10.1017/S0266462305050324.

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J.M., Akl, E.A., Brennan, S.E., Chou, R., Grimshaw, J.M., Hróbjartsson, A., Lalu, M.M., Li, T., Loder, E.W., Mayo-Wilson, E., McDonald, S., MdGuinnness, L.A., Stewart, L.A., Thomas, J., Tricco, A.C., Welch, V.A., Whiting, P. & Mohler, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ*, *29*, 372:n71. https://doi.org/10.1371/JOURNAL.PMED.1003583.

4. Comments on the state of science in person-centred care from an international panel

4.1 Exploring the essence of person-centered care through diverse philosophical perspectives

Vaibhav Tyagi, Sara Wallström, Malin Rex, Annie Jonnergård, Brendan McCormack & Inger Ekman[6]

This is a summary of the conversation into the complex dimensions of person-centered care (PCC), exploring its philosophical foundations and practical implications. Each participant brings unique insights, grounded in diverse philosophical traditions and cultural contexts, highlighting the multifaceted nature of what it means to be a person and how this understanding shapes care practices.

Autonomy and personhood

Brendan McCormack's perspective on PCC is deeply rooted in Kantian ethics, feminist ethics, and hermeneutics. He raises critical questions about autonomy, particularly within the context of older adults. According to McCormack, Kantian ethics' erosion of decisional autonomy often undermines executional autonomy, preventing individuals from being included in their decisions. This dynamic erodes personhood, especially among older people, leading McCormack to advocate for person-centeredness. His philosophical journey through the works of Tom Kitwood, Martin Buber, and Aristotle underscores the importance of relational autonomy and the essence of being a person. In this view, autonomy is not merely about making decisions but about being able to act on them within a supportive relational context.

---

[6] Acknowledgement of the contributions by Jon Petter Stoor.

The life world and social engagement

Inger Ekman's approach to PCC is influenced by Ricoeur and combines teleological and deontological perspectives. Kantian morality is at once subordinate and complementary to Aristotelian ethics because the ethics goal needs to be critically assessed and passed through the examinations of the norm. Ekman emphasizes the "wish for the good life with and for others in just institutions" and highlights the importance of social engagement and justice. She contrasts the GPCC (Gothenburg Person-Centred Care) model, which integrates objectivity and subjectivity, with McCormack and McCance's model, which stresses humanistic caring. Ekman argues that caring is not esoteric but grounded in ordinary, empathetic interactions and acknowledges the physical and phenomenological aspects of personhood.

Inclusivity and eastern philosophies

Vaibhav Tyagi introduces a critical perspective on the predominantly Western philosophical foundations of PCC. He advocates for the inclusion of Eastern philosophies, such as Buddhist and Hindu perspectives, which emphasize interconnectedness and relational identity. Tyagi argues that subjectivity and objectivity are intertwined, challenging the clear distinctions often made in Western thought. He underscores the importance of understanding personhood within a cultural and relational context, where one's identity is shaped by connections with family, community, and environment. This holistic view aligns with the principles of PCC, which aims to create an environment where individuals feel understood and respected in their entirety. McCormack agrees and brings in an Australian indigenous perspective – where collaboration and inclusivity are at the core of his team's indigenous framework of person-centered practice. Tyagi provides a historical example from Bengal famine and emphasizes the need to consider time, culture, social and political factors in "what it means to be a person".

Sacredness and environmental connection

Jon Petter Stoor brings a Sami perspective, emphasizing the profound connection between personhood and the environment. He shares the example of a Sami artist whose life and identity are deeply intertwined with the forest. For the Sami, the land is sacred, and this connection must be acknowledged in PCC. Stoor argues that failing to respect what is sacred to individuals erodes their personhood and well-being. This perspective resonates with the Maori tradition and other indigenous views, where the land is not an "other" but an integral part of one's being. Stoor's insights highlight the necessity of incorporating environmental and sacred contexts into PCC to truly understand and respect the person.

The intersection of philosophical traditions and PCC

The dialogue commented upon here reveals common themes and challenges in implementing PCC across different contexts. A key issue is balancing simplicity and comprehensiveness in care models to ensure they are practical and widely accepted. McCormack and Ekman discuss the need for simple routines to make PCC appealing to professionals, especially physicians. Tyagi and Stoor stress the importance of inclusivity and respect for diverse cultural perspectives in defining personhood.

The conversation also touches on the practical aspects of PCC, such as patient records and digital literacy. Participants agree on the need for single, accessible records that facilitate patient involvement and corrections. They highlight the dangers of reducing person-centered narratives to checklists, advocating for systems that preserve the depth and richness of individual stories. The potential role of AI in summarizing lengthy narratives while maintaining person-centered values is also explored, emphasizing the need for technology that supports, rather than undermines, holistic care.

Challenges and future directions

Implementing PCC in a way that respects and incorporates diverse philosophical and cultural perspectives presents several challenges. One significant challenge is ensuring that care models remain true to core PCC principles while being adaptable to various contexts. The participants emphasize the need for mutual respect, understanding, and collaboration among family carers and patients. This involves recognizing and valuing different beliefs, values, and cultural practices, which can be facilitated through education and training in cultural competence.

Another challenge is navigating the tension between individualized care and systemic constraints. The participants discuss the impact of bureaucratic and technological systems on the delivery of PCC, noting that overly rigid systems can hinder genuine person-centered interactions. They call for more flexible and responsive systems that prioritize the patient's narrative and perspective.

Conclusion

The discussion provides a rich exploration of the philosophical foundations and practical implications of person-centered care. The participants' diverse perspectives highlight the complexity of defining and implementing PCC in a way that truly respects and honors each individual's unique personhood. By integrating insights from Western and Eastern philosophies, indigenous traditions, and contemporary care practices, the dialogue offers a comprehensive vision of PCC that is inclusive, respectful, and deeply attuned to the relational and contextual nature of personhood. As PCC continues to evolve, it will be crucial to address the challenges and leverage the opportunities identified in this conversation to create care environments that genuinely support and enhance the well-being of all individuals.

4.2 Major concepts and attributes of person-centred care

Lovisa Thunström, Angelica Wiljén, Anna-Karin Edberg, Emma Forsgren, Bradi Granger, Annica Backman, Lotta Pham, Stefan Nilsson, Kristín Þórarinsdóttir, Teatske Van Der Zijpp & Kent Stuber[7]

What are the major concepts and attributes of person-centred care?

The major concepts discussed during the session were the ethical foundation, stating the person's unique value, and that PCC is a holistic and relationship-based approach. PCC encompasses physical, emotional, and social aspects of care and emphasizes cultural sensitivity, which means treating patients with dignity and respect, considering their cultural context, individual preferences and values, and respecting their individuality.

The discussions touched on several core attributes, such as communication, and more specifically what constitutes meaningful communication, and that this might vary for each patient. Another attribute was empowerment, whereby in a PC approach patients should be empowered to actively participate in their care decisions and treatment plans. The importance of empowering health professionals and significant others/family members was also highlighted. Further, the discussion raised the issue of feedback, which was seen as crucial, not just in terms of shared decision-making but also in understanding the patient's experiences and fostering a partnership between health professionals, family carers and patients. Feedback is needed from both sides and reciprocity is a central concept in the context of PCC for mutual exchange in the partnership. Further aspects discussed were the importance of coordination and continuity of care.

What remains to be known or is inconclusive/inconsistent?

Sometimes there is an attitude that the humanistic view means acknowledging the person is resourceful, but this can be problematic because what do we do if the person does not have clear resources (e.g. infants or people with severe dementia)?

---

[7] Acknowledgement of the contributions by Christi Nierse and Alexander Olausson.

In this case, the person needs someone to help them make decisions. At other times 'personhood' is ignored.

Shared decision-making does not mean that the patient should decide everything for themselves – there might be a need for compromise – and this is something in the PCC approach that needs to be clarified. The idea that PCC equates to the patient making all the decisions is one misconception that need to be addressed, but research articles tend to be too abstract about this.

There is also conceptual confusion within the field. For example, in Sweden, the health care reform *nära vård* (person-centred and integrated care) uses the words *dokumenterad överenskommelse* (documented agreement) instead of partnership. This could confuse stakeholders.

The link between the healthcare system and the patient's life context and access to care is not sufficiently incorporated within the PCC approach. PCC is influenced by broader systems and discourses, necessitating a systemic approach to address gaps and improve care delivery. A whole system approach and sound policies is the next step, rather than simply trying to include systems.

There are overlaps between different theoretical frameworks of PCC, but they focus on slightly different things. What is the essence of each one of them, and how do they all relate to one another? The concepts are all there in the Santana framework, McCormack framework and the GPCC model.

The GPCC model focuses greatly on the narrative, and it has limitations. It can be hard to implement in organizations, since there is little said about leadership, working culture etc. There are other models (such as Santana's) that accentuate this more, so how can these two models interact with each other?

The PCC discourse centres on practice vs theoretical, abstract knowledge of the field. The GPCC model can be interpreted as a documentation model, but it still leaves health professionals wondering how to implement PCC in their work, and many want more concrete information/instructions. However, if PCC becomes more concrete (less abstract), it might lead to devising checklists, something academia is opposed to, as PCC is not that simple.

In order to do PCC, an open environment where you feel safe to criticize and question authority and ideas is vital. There must be this type of atmosphere. In fact, academia should start by looking at its own working conditions, traditions, and the type of mentality that is transferred onwards. This is something academia has become increasingly aware of – that the working climate is very important.

However, we need to go from model to practice. How do we raise future PCC researchers and health professionals? We need a change of behaviour and culture.

Academia has hierarchies, and sometimes methods of destructive criticism. One does as one has been treated, and if junior researchers copy destructive behaviour and attitudes, we will only repeat history. These types of hierarchies are also seen in hospital environments, with some professions at the top with a lot of power. If those with power only recognize the medical aspects, a patient might not be heard. In this way, both academia and hospitals are barriers to PCC. These hierarchical structures need to be broken down.

We need to work more IN the healthcare setting (and not in theoretical academic settings) to be able to move forward with PCC. Practitioners want to do the right thing, not to make fools of themselves, and they need action plans to lean on, some role modelling and examples of HOW to work. This means researchers/academics need to be close to the practical, everyday work and have conversations with practitioners.

Perhaps facilitators are missing. Perhaps we need something like 'the ten commandments of PCC' to lean on, for example, when asking, what is a good partnership? Rather than generating more models for PCC, we need to develop the existing ones or use and adapt the model that is most applicable to our own setting.

One important and evolving area within health care is technology. Is technology a feature of PCC? Is it a means to an end? It is described as an enabler? It is all about functional communication. We think technological solutions can serve as an enabler for PCC, but they must be functional and meaningful to the patient's care journey. Challenges exist in healthcare systems where different systems do not communicate with each other, hindering seamless delivery of PCC. We need to maintain our focus on person centredness in the development of new tools, looking at how the technology is used and integrated in the clinic and how it affects patients' lives. Patients' needs and goals should always be the starting point. One suggestion made in the discussions was to start small with patients' narratives and then see what emerges. The groups also discussed how technology changes the work for staff, and that this should be acknowledged from the start of a development/co-creation process. Thinking about how technology can help staff in their work, how it will be used and whether the incorporation of tools will add to the burden of work for staff is essential. At the end of the day, is it worth it? PCC requires ongoing evaluation, collaboration, and co-design to address evolving patient needs and improve care outcomes.

Another important area for PCC development is education for future health professionals. How can the current curriculums be improved? How can we keep the essence of PCC, as well as the same focus and understanding, to avoid confusing students? Discussion tools might be needed but also other facilitators, tools and guides to be able to put PCC into practice. What people say they do and what they actually do can be quite different. The education on PCC in clinical settings is also inconclusive, one barrier today being the cost – current systems do not support this kind of care. Moreover, we still rely on an oral tradition whereby staff teach each other and have mentorship, and this only works if people are working together in the same place for a long time (which is rarely the case nowadays).

Policies and guidelines from organisations such as WHO, as well as the Swedish National Board of Social Affairs and Health exist, which means some potentially facilitating structures are in place for PCC at a high political level. However, we still need to make a case for PCC and the practicalities of its implementation. Some structures can be both facilitators and barriers. One example in Sweden is *kunskapsstyrning* (knowledge-based health care), which can be seen as a type of checklist, which is undesirable for PCC, as it sometimes creates too many rules to follow. There are also standardized courses of care, for example, in treating cancer, which is fine if the patient fits all the criteria, but not otherwise (i.e. they have multiple diagnoses). This is where PCC comes in. There is a need to discuss with leaders and practitioners about what is helping, what barriers exist, the type of ward structure etc. One suggestion for opening the lines of communication is to have some kind of structured guide with questions that you can look at and still adapt with PCC, and this is something to reflect on for future development.

4.3 Primary strategies and principles for person-centred care knowledge translation

Kiana Kiani, Angelica Höök, Karl Swedberg, Filipa Ventura, Claudia Silva & Dominic Jarrett[8]

The following model from a cost care project was the starting point for the group discussion about strategies and principles to drive person-centred care knowledge translation. The model is based on a project looking at the type of drivers that should be used to improve health care within a financially constrained environment and in relation to person-centred care. Important factors identified were infrastructure, incentive systems, contracting strategies, technology and quality measures.

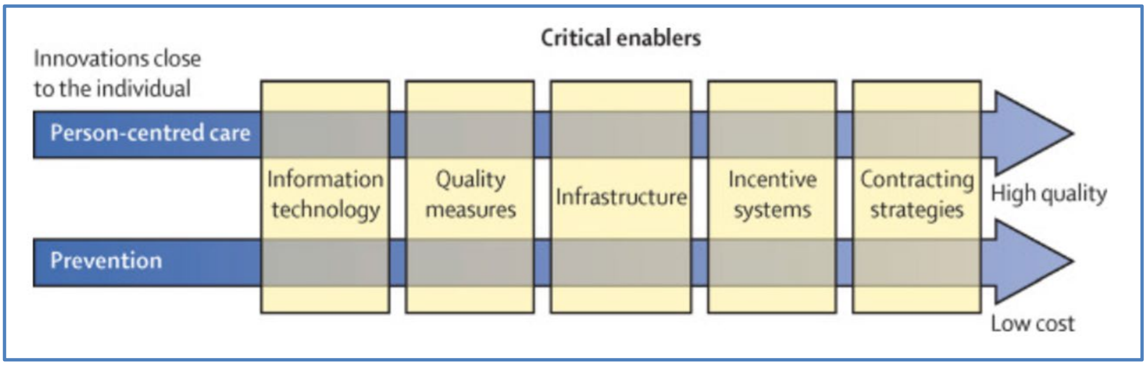


Figure 4.3.1. Healthcare improvements in a financially constrained environment (Ekman et al, 2016; Swedberg et al, 2021)

Summary of discussion points

This model can be seen as translation of theoretical knowledge into practice and can be used as a model for the translation of PCC into action. *People are the first enablers*, so everyone involved needs to understand what PCC is about and get on board. Because PCC is often difficult to implement sustainably, communication must be an underlying factor throughout the process.

We are the changing factor through our interaction with others, and by changing our own behaviour there is a chance others will change theirs.

---

[8] Acknowledgement of the contributions by Mattias Tranberg & Diana Vareta.

One way to involve stakeholders is to use PCC *champions* in the implementation process. When you see someone you admire acting in a person-centred way, they become a role model or a champion. We need champions and multidisciplinary teams to facilitate the implementation process.

In the same way that people are the first enablers, they are also the first barriers for person-centred care knowledge translation. At a micro/meso-level, health professionals might get the feeling that PCC may lead to a "loss of power" for physicians and other health professionals, if patients are going to participate in their care. It is therefore important to identify the *role of every stakeholder and to see the role of the patient* in every part of the process. Currently, evaluations are primarily carried out by professionals, but it is important to recognise that patients should take part in the evaluation too.

Sharing person-centred stories, for example, a story of a partnership, can be a way of involving people in their own care and at the same time help to defuse the misconception among healthcare professionals that involving patients in decisions about their health and considering their perspectives automatically diminishes their professional authority. People value the relational aspects of the experience of being cared for and involvement in decision-making does not often concern clinical aspects, which could be the cause of loss of power.

Leadership and culture are fundamental to supporting people who are willing to lead a change within clinical settings. To make things work in real life it is important not just to see the process as a translation but also as a *co-creation.* It is important to involve key elements within every healthcare context, including at medium management level and with chosen health professionals, who in turn can spread person-centredness and influence the whole team by their actions.

There are other factors that are just as important, such as the *infrastructure* to support translation of PCC into practice. In implementing PCC it is important to recognise *digital solutions*, such as documentation systems, as facilitators of the daily work-life of those who believe in change. Adapting systems to a more person-centred approach, valuing the narrative of the person is fundamental.

Education is also an important part of implementation. We should be aware of what we are teaching our students. In relation to PCC, it is important to teach students what defines a person rather than a patient and to teach them to become better professionals. Making PCC mentors available as part of their training is one way of encouraging this, but investment in education is also needed, with interdisciplinary programmes that facilitate working together, and this must start early on.

Sometimes it may be a long way from the top, where decisions are being made, to the floor, where decisions are being implemented. We need champions at every level to ensure complete follow through. At macro level, despite the existence of different standards, the important thing is to use them, if they are underpinned in a person-centred practice.

Different models (not always labelled PCC) are being used which are not so far removed from the ethics formulated by Ricouer. With so many different perspectives, it is important not to get stuck on definitions but to find a common ground and for different disciplines to *let go of their power* to make implementation easier.

When talking about definitions, we occasionally end up on the borderline between different disciplines, but quite often we are talking about the same thing. Perhaps the boundaries between different professions should be a little blurred because then we can more easily arrive at a real implementation of PCC. Defining roles can be a way of getting away from the feeling that we are losing power. It is often about changing behaviours.

In relation to PCC there is a potential risk of over-defining or over-legislating to the extent that we start to undermine the core aim and values of person-centredness and turn it into a formulaic process. By extension, we may need to think about what can be taken out of the system to create space for people to be human, rather than layering in additional elements.

There may be an opportunity to support champion-led changes within committed clinical teams by creating pressure for change through laws or the authorities' recommendations. The circumstances will be different in different countries, but laws that define the obligation to listen to the patient may make this easier to accomplish in a structured way. It is also important to look at the reach of these standards beyond the country's borders.

Finally, we must also recognise *the role of art, sport and other areas* that help us to connect with our humanity and that help the translation of knowledge and the implementation of PCC.

References

Ekman, I., Busse, R., Van Ginneken, E., Van Hoof, C., Van Ittersum, L., Klink, A., Kremer J.A., Miraldo, M., Olauson, A., De Raedt, W., Rosen-Zvi, M., Strammiello, V., Törnell, J. & Swedberg, K. (2016). Health-care improvements in a financially constrained environment. *The Lancet*, *387*(10019), 646-647. https://doi.org/10.1016/S0140-6736(16)00285-3

Swedberg, K., Cawley, D., Ekman, I., Rogers, H. L., Antonic, D., Behmane, D., Björkman, I., Britten, N., Buttigieg, S. C., Byers, V., Börjesson, M., Corazzini, K., Fors, A., Granger, B., Joksimoski, B., Lewandowski, R., Sakalauskas, V., Srulovici, E., Törnell, J., Wallström, S., Wolf, A. & Lloyd, H. M. (2021). Testing cost containment of future healthcare with maintained or improved quality – The COSTCARES project. *Health Science Reports,* *4*(2), e309. https://doi.org/10.1002/hsr2.309

4.4 Prerequisites, mediators and expected outcomes for person-centred care knowledge translation

Stina Mannheimer, Lena Rosenlund, Chris Graham, Andreas Fors, Souzi Makri, Kristina Vladimirova, Karolina Mark, Diane Slater, Sneha Jabbar, Magdalena Walter, Annamari Laitinen & Elvis Imafidon[9]

Knowledge translation

The group started by defining knowledge translation as a dynamic and iterative process that includes synthesis, dissemination, exchange, and ethically sound application of knowledge to improve health, provide more effective health services and products and strengthen the health system. The gap between knowing the benefits of PCC and effectively implementing it in practice was emphasized; how can we go from knowing to doing? Some definitions of 'knowledge transfer' are essentially 'research into practice', whereas some also include dissemination of research. However, this was compared to the concept of knowledge transmission, that considers how to make knowledge more accessible to practice. It assumes that producing knowledge would not make much sense to the general public, if not translated into something more accessible. The group decided on using a broader definition of knowledge translation that also included the concept of knowledge transmission. It was agreed that knowledge translation can happen on multiple levels: in health systems and among health professionals but also among patients or patient groups. The group also agreed to take a broad view, with an open scope to the discussion embracing different contexts and perspectives.

Prerequisites for PCC knowledge translation

To address the challenge of moving from the theoretical understanding of Person-Centred Care (PCC) to its practical application across an entire healthcare system, we need to consider several key factors: policy decisions, leadership, education, culture, economic incentives, and strategic implementation steps. Successful person-centred culture implementation requires sustained effort, time for

---

[9] Acknowledgement of the contributions by Cis F.P.C. Lijten and Asma Sabri.

reflection and leadership commitment. A consensus definition of what PCC means and how we define a person within the context of PCC also provides a foundation for the practices.

Judging by the good examples highlighted during the GCPCC conference and in different healthcare settings, it would appear that the successful implementation of PCC policy decisions and effective teaching of PCC in higher education nursing programmes tends to be isolated to specific projects or units, rather than being a widespread cultural change across the healthcare system. Projects led by only a few facilitators are also very vulnerable. How can we implement a person-centred culture in the whole healthcare system? And how can we make it sustainable? Is it better to implement it in steps? An example was given from Belgium, where they implemented goal-oriented care.

Training and education

We discussed prerequisites in terms of what skills a person needs for PCC. Most important was a positive attitude towards person-centred care, willingness, and empathy – then you can adopt or learn the skills you need. Among those choosing to work as nurses or allied health professionals there should be a willingness to work and collaborate with patients and their relatives, and to be involved in improving healthcare. In order to reach a state of collaboration between health professionals we need to integrate PCC into the curriculum and ensure students can carry this into practice, so that everyone works towards the same goal.

Patient participation

When it comes to educating (and implementing) health professionals in person-centredness, patient representatives should be involved, as patients can provide a better understanding of real-life feelings and thoughts. We also need to better understand how to teach patients to actively participate in their care, shared decisions, use of own resources etc. and how to foster this cultural change in the general population. Patients who want to be active and involved need better e-health solutions for coordination and communication with different health professionals; they need a place for their own documentation, access to shared documentation, self-management advice and learning systems, as well as the ability to prepare for and influence the agenda before visits.

Organizational support

The need for support from the organization was emphasized, noting the difficulty of working alone without team support. Management support on all levels is crucial to sustain a person-centred work approach. It was emphasized that mid-management are not always conscious about their important role in sustaining cultural change, being supportive and enabling professionals to feel passionate about their role, which can be seen as a prerequisite for delivering PCC. To go beyond a 'one-size-fits-all' model, PCC must be normalized within the system and that normalization must come from the organizational leadership. This can be described as normative legitimacy – the idea that throughout the organization PCC is an accepted part of the culture and 'how we do things'. Interprofessional cooperation was also pointed out as a foundation for PCC.

Barriers and facilitators for PCC knowledge translation

Workplace culture

One concern was sustainability, as nursing students who had been taught PCC forgot about it after some time. This was because in daily practice they simply had to get on with tasks and did not have time to reflect on person-centredness or have enough support to carry it out. The prevailing culture was also a factor in losing sight of a person-centred approach. For example, lack of autonomy as a nurse, with "all the rules and advice from doctors", was pointed out as a barrier to making individual moral decisions and curbed health professionals' freedom to deviate from standard practices. Our discussion also highlighted the tension between a desire to act autonomously and things like checklists. There are good reasons for having checklists, and for junior health professionals they are crucial, as it takes years to develop intuitive thinking in clinical situations, but they can restrict how we act.

Hierarchy, lack of understanding and insufficient knowledge were pointed out as major barriers to implementing and safeguarding PCC. On the other hand, openness, sense of equality, inclusiveness, psychological safety, relational continuity of care, multidisciplinary working and shared responsibility were pointed out as facilitators for PCC. Respect for people's different views is fundamental, and from the philosophical literature we can relate to the concept of epistemic justice (e.g. Fricker, 2007; Carel, 2008). We discussed how to bring people from different professional groups together and encourage dialogue as an intervention to reduce hierarchy and power distance between clinicians and management, as well as between nurses and physicians. Of further note was the perception that PCC is "what we are already doing", which makes implementation a challenge, if changes are yet to be made in the workplace culture.

Costs and economics

Costs and economics were also discussed, highlighting that implementing PCC was expensive at the outset. This could be a barrier to overcome, especially now when healthcare systems are struggling with their finances. In order to feel safe in making priorities according to PCC principles, clinicians need to know about cost effectiveness. Does it have to be expensive to implement?
Economic models that do not reward PCC can hinder its adoption, as seen in primary care units focusing on patient volume and diagnoses instead of person-centred care. Certification programs, like those in the US (see https://www.planetree.org for example) could help standardize and promote PCC practices. Could we have accreditation for things like reimbursement and education? Or for showcasing nice places to work, for example, 'Magnet hospitals'.[10]

Time and resource constraints

The discussion focused on the perception that PCC implementation requires more time and resources, which can be a barrier in busy clinical settings. It also takes time and resources to maintain a person-centred culture. Clinicians often feel implementing person-centred care creates an extra burden for them. And when there is a shortage of nurses, how can we facilitate and motivate new implementation projects? Can we show that working more person-centred can save time? This is something we need to focus on, as healthcare costs can potentially be reduced in the long run due to more efficient and effective care practices. Can we show that healthcare professionals can do less but work more effectively, and are there things they could stop doing or do less of?

There were also concerns about how to deliver person-centred care when patient meeting times are very limited, or in an acute situation, when there is no time to understand what that patient wants or needs. The argument for facilitating PCC regardless of time was preparing before a meeting. The view was that it is not about physical time, it is about what you want to be and how you act, so this is in

---

[10] Magnet hospitals are institutions where nurses are empowered not only to lead patient care but also to spearhead management, scientific discovery, and improvement of efforts. Accredited magnet hospitals are known for providing high-quality care, achieving high nurse retention, and improving both patient outcomes and satisfaction (Rodríguez-García et al., 2020).

the culture. In health organizations we often treat the patient first and know the patient later, which is antithetical to the idea of PCC.

Context, language and person

Patients and families should be welcomed to get involved in building opportunities for themselves and sharing their experiences. We can then make a habit of engaging them as part of practice. While communication and being present are soft values, they are no less important, even though much focus in healthcare is on hard facts and checklists. Evidence shows there is a demand for fidelity in the implementation of interventions. However, within PCC, fidelity is all about morality and ethics rather than repeating particular actions.

Not having a fixed definition was mentioned as one barrier, although we do have principles that need to be adapted to the specific context and person. One misconception was that PCC is just for long term conditions, not for acute settings. However, there was agreement about how person-centredness is also important in acute settings, although considering the context is key, as person-centredness in an acute setting will not look the same as for patients with long-term conditions. So, the context itself is not a barrier – we simply need to adapt to it when implementing person-centredness. It follows then that we need to adapt not only to the context, but also to the specific scenario, moment in time, and individual person, and that could mean something different the next day. The patients' understanding, needs and preferences can change day by day.

We discussed how to communicate PCC principles effectively to both healthcare professionals and patients. National campaigns and patient organization involvement are crucial for promoting PCC culture among patients *and* healthcare providers. One barrier identified when translating knowledge about PCC was the language. Many of the words we use in theory, such as 'partnership' or 'resources' are not words we can use when we talk to patients. Therefore, we need more studies on how to also translate the language – the descriptions – in terms health professionals and patients can use in clinical meetings.

Outcomes of person-centred care knowledge translation

Healthcare according to PCC principles, when caregiver and patient get to know each other over time and as persons, can lead to much more meaningful interaction. Patients will see healthcare systems as more accessible – as a safer space in which they feel validated and seen as individuals, not just as a disease.

Changing the perspective from patient to person and establishing openness and trust can lead to a transition of knowledge from the person. If that knowledge of their personhood is passed on, the patient becomes a facilitator – we just have to find the mechanism that makes that happen.

Our discussions emphasised the health professionals' perspectives: working with a PCC approach generates the feeling that although we cannot solve all of the patient's problems, they will feel at peace. Another benefit is that they will not need to contact the hospital as frequently, which can be an immediate positive effect for both the patient and the healthcare professionals. PCC also has positive benefits for health professionals in terms of the care experience and time efficiency. An example given was: "if you're doing a night shift and you take time before the first round on the ward to give more time to the patients, the night will be quieter".

It was agreed that when patients have a good care experience, it can enhance the health professionals' experience. As a result, these can provide better care and feel better in their role, leading to a virtuous circle. Health professionals are under a lot of pressure from all kinds of demands. The point was made that we want to do the best for our patients, but many times we leave work asking ourselves, "did I do enough?" It was noted that the positive effects of PCC on patients could rub off on the professionals: "When you see that the patients are at peace, you can relax a bit and feel satisfied, even though you couldn't solve everything." This changes the focus from bringing someone's body to perfection to making them feel well. It contrasts well with the medical model, that can be seen as a battle to cure every illness and achieve immortality, which the profession is always doomed to lose. It was agreed that PCC, on the other hand, is about recognizing personhood and therefore there are broader goals of health and well-being. PCC is about building connections and trust, which does happen in healthcare today, but we need to find ways to make it more commonplace.

What remains to be known or is inconclusive/inconsistent?

We need to develop a way of implementing PCC at a broader level, which can be complex, as implementation is dependent on context and cultural specificity. We cannot expect to do the same thing in the same way everywhere and have the same results. Also, we need to find ways to address staff members who do not have good communication skills or who do not want to take part in PCC implementation. Self-reflection is important but might be hard for some.

References

Fricker, M. (2007). *Epistemic injustice: Power and the ethics of knowing*. Oxford University Press.

Carel, H. (2008). *Illness*. Routlege.

Rodríguez-García, M. C., Márquez-Hernández, V. V., Belmonte-García, T., Gutiérrez-Puertas, L., & Granados-Gámez, G. (2020). How magnet hospital status affects nurses, patients, and organizations: A systematic review. *AJN The American Journal of Nursing*, *120*(7), 28-38. https://doi.org/10.1097/01.NAJ.0000681648.48249.16

4.5 Micro-meso-macro links and interrelations for person-centred care knowledge translation

Malin Lindberg, Lisa Goldkuhl, Salwan Diwan, Sepideh Olausson, Maria Santana, Axel Wolf, Anneka Knutsson, Jessica Gish, Sarah Murphy, Anna-Greta Ledin, Camilla Anker-Hansen, Jacqueline Wilson, Eliane Castillio, Hanna Gyllensten & Håkon Johansson [11]

Despite extensive research over the past 30 years, the integration and implementation of Person-centred care (PCC) remains inconsistent across various healthcare settings. To understand and improve PCC, it is crucial to examine the interrelations of the micro-meso-macro levels of healthcare systems, identify gaps and explore strategies for effective knowledge translation.

Micro level – personal and interpersonal level

The discussion highlighted the importance of including patients, and also their family carers and significant others in care processes. This involvement can bridge gaps in understanding patient needs and improve care outcomes. Most studies have been conducted in hospital settings, and have neglected other critical areas such as homecare, primary care, institutions for people with disabilities, and social care. There is also limited research on specific populations, such as individuals with cognitive impairments and children.

The importance of turning PCC knowledge into real-world application was emphasized. There is a need for support and systematic collaboration. Change agents or facilitators and coordinators can serve as effective facilitators for driving change. Active participation in role-playing was suggested to facilitate knowledge transfer. Collecting experiences at different levels was also highlighted, questioning why the focus is often on negative events in healthcare when positive examples should also be highlighted. There is a need to focus more on the positive aspects, not just the negative ones. Exchanging experiences and emotions can bring change.

---

[11] Acknowledgement of the contributions by Bjørg Elisabeth Hermansen.

What remains inconclusive:

- How can PCC strategies be effectively extended to diverse care settings beyond hospitals?
- What are the best practices for involving family carers in PCC, particularly in non-hospital settings?
- How can PCC be tailored to meet the needs of specific populations, such as those with cognitive impairments and children?

Meso level – organisational structures

The meso level involves healthcare organisations and community structures that support PCC implementation. Effective PCC requires collaboration and partnership among various stakeholders, including government agencies, healthcare organisations, and communities. However, our discussion indicated that many frameworks and strategies are derived from Western contexts, which may not be universally applicable. Additionally, there is a need for greater integration of PCC concepts into healthcare education to prepare future leaders.

The discussion at meso-level focused on how structures and systems need to change to support person-centred care. It was emphasized that it is crucial to engage with leaders, as organisations are composed of people and it is the responsibility of leaders to implement and model a PCC approach. Recruitment, education, and future perspectives were highlighted as critical areas of focus. The design of language and good leadership were pointed out as crucial factors.

What remains inconclusive:

- How can we develop and implement PCC frameworks that are adaptable to different cultural and organisational contexts?
- What are the most effective ways to integrate PCC principles into healthcare education and training?
- How can healthcare organisations model PCC internally to support their employees and ensure consistent practice across all levels?

Macro level – policy and systemic level

At the macro level, policies and systemic changes are essential for integrating PCC into the healthcare system. This includes creating legislation and policies that mandate PCC practices to ensure accountability and provide resources for implementation. However, there is often a disconnect between policymakers and healthcare providers. Effective PCC requires both top-down mandates but also grassroots input to ensure policies are practical and grounded in everyday healthcare realities.

The discussion at macro level highlighted cost-effectiveness and its impact on all levels. It was emphasized that the greater focus on costs at macro level affects each level. Measuring costs and understanding group dynamics were considered important for ensuring safety and acceptance. The cost-effectiveness at micro level impacts macro costs, and it is essential to 'speak the language' at each level. There needs to be a shift towards speaking different languages at each level, and knowledge must be translated both upwards and downwards. Ensuring that patients' voices are heard through barriers was also emphasized, with a focus on including patient and public voices in the work.

The role of clear leadership in successful implementation of PCC was discussed. Designing clear language and good leadership were seen as crucial at all levels of organisations. The question of how to actually implement these strategies was raised, highlighting the gap between knowing what to do and knowing how to do it.

What remains inconclusive:

- How can policymakers be better educated and engaged in the principles and benefits of PCC?
- What legislative frameworks can effectively support PCC implementation and ensure accountability without overburdening healthcare providers?
- How can we create systems that facilitate continuous feedback between policymakers, healthcare providers, and patients to refine PCC practices?

Recommendations based on the discussion

Expand research beyond hospitals: More research is needed in diverse care settings, including homecare and primary care.

Involve family carers and significant others: Developing strategies to include family carers and significant others in care processes is crucial. This involves creating supportive policies and training healthcare providers to engage with families.

Terminology: There has been significant discussion about the terminology used in PCC. Despite this, something crucial seems to be missing. A lot of research exists in fields such as public health, midwifery, and medical anthropology that might not explicitly use the term 'person-centred care' but fundamentally addresses similar concepts. For instance, medical anthropology explores health belief systems and traditional health systems, which can provide valuable understandings into PCC. In midwifery, the focus on woman-centred care aligns closely with the principles of PCC. However, there is an unnecessary power struggle between nursing and midwifery, which could hinder the integration of these understandings.

Cultural adaptation of PCC frameworks: PCC frameworks should be adaptable to various cultural and organisational contexts. Research should explore how different healthcare systems, especially in non-Western countries, can implement PCC effectively. Understanding the barriers to effective PCC implementation is crucial. Different healthcare systems face unique challenges and performance variations that need tailored strategies. Looking at other systems and learning from their successes and failures can provide valuable knowledge. For instance, fragile healthcare systems in various countries might benefit more from implementing PCC over traditional medicalised approaches. The WHO reports are a valuable resource for guiding these efforts.

Integrate PCC into healthcare education: Incorporating PCC principles into the curricula for health professionals' education is essential, as the students are the future leaders.

Policy and legislation: Governments should enact legislation that mandates PCC practices and holds organisations accountable. Policies should be developed collaboratively with input from all stakeholders, including patients, healthcare providers, and policymakers. Involving macro level stakeholders in future (nurse/midwifery) conferences is also essential for the advancement of PCC. Their engagement ensures that the policies and frameworks supporting PCC are well-informed, practical, and effectively implemented across the healthcare system. It is not enough to simply convey the importance of PCC to the politicians; they need to be present, engaged, and involved in the discussions. The extensive body of work on PCC needs to be shared and understood by those who can influence policy and practice. Effective PCC requires the involvement of communities and a commitment to shared decision-making processes, which are currently lacking clear intersection across different levels of the healthcare system. Government entities, with their varying interests and management structures, often face political challenges that hinder true partnership. It is vital for these decision-makers to understand the concepts and implications of PCC. A shared commitment to PCC necessitates clear legislation that defines rules and responsibilities. Building a legislative framework at the macro level can help ensure accountability and provide a foundation that trickles down to the meso- and micro levels. To bridge these gaps and foster a culture of effective PCC, it is essential to provide concrete examples of what shared decision-making looks like in practice. This involves a significant effort to clarify, educate, and support the translation of PCC principles into everyday actions. The interlinkages between different levels of the healthcare system need to be clear. People in leadership positions must grasp the essence of PCC and interpret it correctly for their organisations.

To drive change, there must be a strategic approach to **advocacy** and **lobbying.** Engaging with politicians and decision-makers is crucial. Healthcare professionals and organisations need to actively participate in policy discussions and demonstrate the benefits of PCC. This involves not just communicating the value of PCC but also showing its practical implications and cost-effectiveness.

Upscaling: While there is substantial research on PCC, much of it is not scalable. We need to focus on identifying the minimum requirements for PCC and determine which populations would benefit the most. Currently, efforts are scattered, and a more targeted approach is necessary. Conducting cost-benefit analyses and considering the social costs of healthcare, such as the impact of trauma on individuals and communities, will help highlight the value of PCC. Moving from a reactive to a proactive approach in healthcare investment is essential. Metrics, like length of hospital stays and rehospitalisation rates, are not sufficient; we must also consider quality of life and social well-being. Human values and empathy are core components of PCC and should be central to discussions about its implementation. For example, the European data-sharing initiative illustrates the need for patient trust and engagement. Patients are more likely to share their data if they feel listened to and valued by the healthcare system. Measuring the actual costs of healthcare practices and the benefits of PCC, both financially and socially, is crucial. The power and money associated with data further emphasise the importance of trust and PCC practices.

Leadership and organisational support: Strong leadership is crucial for the successful implementation of PCC. Healthcare organisations should model PCC principles internally to facilitate a culture that supports and values person-centred practices. To effectively integrate PCC at the meso level, we need more nurse- or midwife leaders, as well as nurse/midwifery researchers in leading positions. Their expertise in PCC values can provide evidence-based knowledge and strategies to guide implementation. Moreover, healthcare organisations often face inefficiencies due to unclear roles and a lack of coordination. There needs to be a concerted effort to address these inefficiencies by clearly defining roles and responsibilities to improve communication and ensure that providers have the support they need to implement PCC.

Focus on cost-effectiveness: Highlighting the cost-effectiveness of PCC is vital for gaining support from policymakers and healthcare administrators. Research should focus on demonstrating the long-term financial benefits of PCC, such as reduced hospital readmissions and improved patient outcomes. Greater emphasis needs to be placed on the digitalisation of healthcare systems to support PCC. If it is well-known that PCC is both cost-effective and beneficial, then the cost of not implementing these practices becomes an avoidable burden on the healthcare system.

In summary

Education, cost, and leadership were the key factors brought up during the discussion. Education ensures that future healthcare professionals understand and can apply PCC principles. Demonstrating the cost-effectiveness of PCC is essential for gaining support from policymakers and stakeholders. Strong leadership is needed to navigate the practical challenges and advocate for policies that support PCC. Focusing on these areas could bridge the gaps between micro-meso-macro levels, and enable implementation and sustainability of PCC.

4.6 Practice implementation

Salma Pardhan, Jakob Wenzer, Erna Haraldsdottir, David Edvardsson & Reini Haverals [12]

Fields with strong examples of practice implementation with potential to act as benchmarking partners

There was a consensus in the group that it is more challenging to find strong examples of fields to be used as benchmarking partners than it is to find components of theories, skills, etc. that are useful. Combined together, these individual cases, scenarios and studies could act like the spokes of a wheel, providing a system-wide perspective of the ideal case that can be used as a stylized benchmark or an idealized goal for PCC. For example, Inger Ekman's research on cardiovascular studies could be used as a guiding principle for developing a benchmark, and further wisdom could be gleaned from the work done on nursing homes in Norway. Nevertheless, there are a few fields of care that are more 'fertile grounds' for the application of PCC from where one can draw examples of successful or meaningful implementation. These include palliative care, paediatric care, the health insurance industry, and possibly primary care.

Palliative care

This is an interesting space that can foster the application of PCC effectively, as the values and purpose that support the principles of PCC are better aligned with that of the palliative setting of care, especially in relation to patients at end of life.

The palliative care setting provides many examples of successful PCC usage, as there is more freedom to provide PCC here than in other care settings. For example, a hospice in Scotland allows patients to engage directly in building their healthcare plans and assessing needs, leading to a higher sense of patient empowerment.

Although palliative care has provided good examples of mobilizing PCC, much more is needed in order to understand the drivers promoting PCC in this area and the 'system' within palliative care that is influenced. In particular, we need to

---

[12] Acknowledgement of the contributions by Amélie Cransac, Malin Johansson Östrbring and Tayue Tateke Kebede.

further investigate how PCC influences palliative care, and how palliative care practices influence PCC delivery.

Health Insurance

The health insurance industry and digital health spaces are good places to find examples of principles that can be applied to PCC.

In the health insurance industry, areas of particular interest are those related to health promotion and prevention, as there may be a financial incentive for people to return to health using a person-driven solution. This tailored perspective may increase concordance and result in less expensive measures, alternatives and interventions. Nevertheless, health insurance companies may find it more challenging to apply PCC when it comes to reimbursement for health services used.

Paediatric Care

Paediatric care is another area that may provide examples of patient-centred care principles which we can draw on. Here, providing PCC helps facilitate the development of a non-threatening environment. However, much more research is needed to understand just how person-centred paediatric care is, and to identify salient examples of PCC within paediatric care.

Generic knowledge identified

PCC needs to be perceived as an initiative that goes beyond curative practices and goals. Areas that are less resource intensive may find it easier to adopt PCC but this is not a determining factor, as shown by paediatric care, which is both resource intensive and curative yet has good examples of PCC implementation.

We reflected on the questions, "Why might PCC work well in some areas of healthcare (such as palliative care and paediatric care) and not so well in other areas (such as cardiac care)? What could lead to this cultural/practice difference?" To begin with, one unifying reality is that PCC works well in areas (such as paediatric and palliative/hospice care) which do not require strict lists of items, routines or guidelines to be followed as part of the patient's care regimen.

In paediatric care, health professionals are encouraged to see their patients' uniqueness, and to provide care on an individual basis. In palliative care, the aim is not curative but rather comfort. Conversely, in cardiac care, for example, the care provisions are more systematic, recurrent and regimented, with patients presenting issues in a similar fashion and thus receiving more organized and systematized treatment. Consequently, areas of healthcare that focus on the curative may not appreciate PCC as much as those areas that focus more on comfort and palliative care.

Medical practice fields that are more heavily reliant on evidence-based decision making may also find it more challenging to adopt a person-centred approach, especially if the evidence is heavily sourced from random controlled trials (RCTs). In particular, guideline-driven areas of healthcare may find it difficult to adopt a PCC approach to care, especially when guidelines are more strictly adhered to and accountability is assessed on how well the guidelines are applied. For example, cardiac care is heavily influenced by RCT-based evidence and therefore has substantial guidelines, while there are no similar guidelines for paediatric care.

It is more challenging to apply PCC in situations where guidelines are too restrictive. In such circumstances, it is important to question where the evidence is coming from, who created the evidence, and how it was created. Evidence-based medicine comes from evidence with strict inclusion criteria which may not reflect the individual person. Essentially, guidelines-based care assumes that the person comes from the evidence, which is an assumption taking many liberties.

For areas that have high uncertainty of care and less agreement of care, there is a sense of chaos lending to more opportunities for interpretation, as there may not be any concrete guidelines at all or the guidelines may be too open or conflicting. In our view, these are the areas that may be more open to using PCC.

Regulations, laws, and the healthcare system have made the adoption of PCC difficult and uncomfortable. Often, it is easier to identify what is not working or making things difficult than to identify areas that actually do work.

To successfully implement PCC, we need to step away from risk aversion. When we are relieved from the responsibility of adhering to a certain way of doing things, we open the space allowing flexibility and allowing the person to be at the centre. It follows then, that the obstacle to successful implementation of PCC could be rooted in accountability. When accountability is reduced, we are able to open up space for empowering both health providers and patients. Essentially, healthcare providers will be more inclined to partner with patients when they do not feel weighed down by responsibility for the decisions made or having to deal with the consequences of not strictly adhering to practice guidelines. Essentially, when we can share the risk (with patients), we can open the space to include the patient. And to include them, communication must be conducive to creating a rapport. This makes the patient feel like they are being taken seriously, and are being treated with respect.

We need to know more about systems and legislations to help identify areas that are barriers to PCC, as well as further investigate areas that can be used to help promote or advance PCC.

5. Comments on the integration of person-centred care and precision health

Axel Wolf

The integration of precision health and person-centred care – a necessary coexistence

In the modern healthcare environment, precision health and person-centred care are two indispensable approaches that must coexist for sustainable and equitable patient care. Although these two paradigms are frequently discussed in isolation, they are in fact complementary and should be integrated in order to address both the biological and relational aspects of healthcare.

The concept of precision health can be defined as "A Data-Driven Revolution". Precision health, which has its origins in the personalized medicine and later precision medicine movement initiated by the 1990 Human Genome Project and the former US President Barack Obama's 2015 precision medicine initiative (Jørgensen, 2019), is a field that uses large datasets and advanced analytics, including genomics and machine learning, to develop tailored medical predictions, diagnostics and treatments. It employs genetic information, biomarkers, and environmental factors to develop highly individualised treatment plans.

The convergence of data analytics, not least through all the sensors around and on us, our capabilities for superfast transfer, storage and analytics of enormous amounts of data, advanced machine learning *and* regulatory advancements are significant factors contributing to the growing development and rapid implementation of precision health. While this development has advanced further in fields such as medical imaging and oncology, the rapid advances in many other specialities and contexts create a unique opportunity for innovation and integration, allowing for the creation of highly personalised predictions, diagnostics and treatments based on the unique phenotypes of patients. This encompasses the utilisation of sensors and environmental data – the Internet of Things (IoT) – thereby extending our comprehension of health beyond the domain of genetics, as will it also broaden and blur the boundaries of healthcare systems and its delivery.

What type of data is being considered?

It is nevertheless important to ensure that precision health does not rely on a single type of data. Instead, it must encompass comprehensive, multidimensional data that includes not only biological, environmental and social data that can be observed, but also 'data' as experienced and narrated that puts relational, social, and environmental aspects into the perspective of the patient living with the illness. This approach guarantees that treatments are not only medically optimised but also aligned with the patient's personal needs, capabilities, networks and circumstances. In the ongoing dialogues between health professionals, patients and their family carers, the precision of treatment and care is elevated through shared understanding, collaboration and co-creation. When health professionals and patients come together as partners, they each bring essential perspectives to the table (Britten et al, 2020). The health professional contributes with health care, medical expertise and data-driven insights, while the patient offers their lived experience, values, capabilities and personal goals. This partnership refines the precision of care, and as this dialogue deepens using a systematic PCC approach, the lines between clinical management and self-management blur, leading to more effective, equitable and sustainable person-centred healthcare outcomes. The objective is not merely to treat the disease but to empower the patient and relatives through this partnership, thereby enhancing their self-efficacy, quality of life and medical outcomes.

Historically, precision medicine and person-centred care have sometimes been viewed as opposing models, each representing different priorities and perspectives in healthcare. Precision medicine focuses on optimizing medical outcomes by harnessing objective biological data, offering treatments tailored to the individual's phenotype and genotype. Person-centred care places emphasis on the partnership between patient and professionals, and by empowering the patient through incorporation of their experience, values and personal goals. These approaches are often seen as residing on opposite ends of the spectrum, hence dividing the biological body in some aspects from the experience of illness. However, this separation is problematic. In reality, to achieve truly comprehensive healthcare, precision health and person-centred care must be integrated. Combining the strengths of both models and different perspectives allows for prevention and treatments that are not only scientifically precise but also responsive to the patient's personal needs and circumstances, bridging the gap between clinical data and human experience.

Hence, I argue that the optimal approach for modern healthcare and social welfare is to integrate different perspectives, starting by not separating the biology of the body (in our case, WHAT is a patient?) from the experience of illness (WHO is the patient?). This is aptly illustrated by a quote from Tomas Tranströmer's poem *Night vision* (1970): "two truths approach each other, one comes from within, one comes from outside, and where they meet, one has the chance to see oneself". This shows that when different perspectives meet, they need to be co-created into an understanding, such as in the meeting of perspectives during a care encounter between healthcare professionals and patients. Likewise there is a need for convergence between precision health and person-centred care.

Incorporating precision health with person-centred care facilitates a more integrated approach to healthcare, whereby the body as an object and its biology cannot and should not be separated from the patient's illness experience. For example, when patients present themselves to the clinicians within a healthcare setting (or within their own home), they do so with both an experience of signs, symptoms, living/adapting to the illness and their own goals. Integrating these approaches allows us to better combine the objective, physiological signs of a disease, but also the subjective burdens it places on the patient. The objective side includes measurable, observable signs such as physical symptoms, lab results and imaging findings. However, the subjective burden and adaption are equally important, encompassing the psychological and social impact of the illness on the patient's daily life, motivations and goals. This includes how the patient feels, their emotional response to the illness, the effect on their quality of life and the challenges they face in their personal and social environments. By integrating perspectives, we can develop health and care plans that are not only medically sound but also address the patient's overall well-being, leading to more effective and compassionate care. The challenge I would argue today lies in the precision health algorithms that build mainly on objective 'historical' data that is biased towards a medical perspective.

The next step in this evolution is to advance towards 'precision healthcare'. This term marks a shift from 'personalized medicine' to a broader, more inclusive approach that takes into account external and environmental factors, in addition to individual biology. This expanded perspective is crucial for enhancing our ability to predict, prevent, diagnose and treat diseases and promote health more effectively. It is imperative the discussion encompasses commercial, environmental and social determinants of health (both negative and positive drivers, not least pre-existing economic, social and racial inequities) in order to gain a comprehensive understanding of and governance strategies for health within equitable and sustainable healthcare systems. The involvement of patients in the collection of data through social movements, such as general citizen science and more specific patient and public involvement (PPI) strategies, are becoming an integral aspect of healthcare. The future of healthcare necessitates a collaborative model between healthcare providers and patients wherein knowledge is jointly constructed (Siira & Wolf, 2022). As we progress, it is imperative that precision health and person-centred care are not treated as isolated concepts. The integration of these two approaches, from both a research and a practical standpoint, will hopefully facilitate the design, development and delivery of a more precise person-centred integrated care system. However, we need more evidence (both in terms of efficacy and effectiveness) and practical experience of this integration in different healthcare contexts (including health promotion and prevention) and diverse populations, as well as with different healthcare stakeholders and workforces.

Figure 5.1. The eco-system for futureproof equitable and sustainable healthcare systems

One area of increased and anticipated focus are quality registers that incorporate PROMs (Patient-Reported Outcome Measures) and PREMs (Patient-Reported Experience Measures). To effectively co-create, design and implement PROMs and PREMs in clinical decision-making, these registers must play a central role in capturing the person-centred dimensions of healthcare. This need is especially relevant as digitalization expands, with sensors on our wrists, phones and even in environments such as our cars increasingly surrounding us (Figure 5.1). As the potential to collect data from different contexts and environments rapidly increases, the line between where healthcare starts and stops will be blurred, making commercial, environmental and social determinants of health important factors to incorporate into the discussion when integrating precision health and person-centred care. It is therefore crucial to remain vigilant about potential biases that could be built into precision health algorithms and systems. Without careful governance, as well as regulation of algorithms and data sources used, we may inadvertently reinforce existing inequities, impacting the vision of quality, sustainability and equity of care. Hence, the vision of person-centredness is of fundamental importance in the research, design, development and implementation of new technologies and service innovations.

The incorporation of data-driven precision health and person-centred care creates a more customised approach, where prediction, prevention, promotion and treatments are tailored not only to the disease but also to the individual's resources, capabilities and needs. In doing so, we move towards a future where healthcare provides health and care to more people, and ultimately needs to be more precise in co-creating and co-delivering effective, equitable healthcare ecosystems.

References

Britten, N., Ekman, I., Naldemirci, Ö., Javinger, M., Hedman, H., Wolf, A. (2020). Learning from Gothenburg model of person-centred healthcare. *BMJ*, *370,* m2738. https://doi.org/10.1136/bmj.m2738

Jørgensen, J.T. (2019). Twenty Years with Personalized Medicine: Past, Present, and Future of Individualized Pharmacotherapy. *Oncologist*, *24*(7). https://doi.org/10.1634/theoncologist.2019-0054.

Siira, E. & Wolf, A. (2022). Are digital citizen panels an innovative, deliberative approach to cardiovascular research? *European Journal of Cardiovascular Nursing*, *21*(3), 287–291. https://doi.org/10.1093/eurjcn/zvab132.

Tranströmer, T. (1970). *Mörkerseende*. Författarförlaget.

6. The editors' reflections on ways forward in the field

Axel Wolf, Emma Forsgren, Ida Björkman, David Edvardsson & Joakim Öhlén

This report aims to take steps towards reporting the state of the science in person-centred care, with the goal of providing an overview of the current knowledge. In this final chapter, we consider the broad range of fields related to person-centred care that are important in moving towards further comprehending the state of science in person-centred care. First we reflect on the contributions of the previous chapters, and follow on from this by considering other areas relevant to furthering our understanding of the broader knowledge base of person-centred care.

The contributions

This report includes a presentation of major frameworks as related to person-centred care and reviews of current recent research literature in the field. The four included frameworks are well represented in original publications (see Appendix for suggested readings) and further utilised and applied in a broad range of literature. Specifically, the five reviews focused on the scope of the larger field of person-centred literature, person-centred practice for people with cardiovascular conditions, implementation of person-centred care for older people in out-of-hospital settings, leadership dynamics and person-centred practices, and costs and associated health outcomes of person-centred interventions. However, the included reviews are necessarily limited due to the vast amount of literature available. The fact that different terms (and both similar and different conceptualisations) are used for the notion of person-centred care is a clear obstacle to presenting a comprehensive overview, thereby risking fragmentation of knowledge and presenting a barrier to the implementation of research-based policy and practice development.

In addition to the frameworks and current reviews, this report includes the reflections and comments of international expert panels and GCPCC conference participants, highlighting what the bulk of PCC knowledge is and where the knowledge gaps are in relation to core theoretical foundations and modes and strategies for translating person-centred care into practice. These reflections and comments are thorough and comprehensive, thanks to all the contributions of international scholars, researchers, students, health professionals, healthcare leaders and patient/user partners. Although the participants were primarily active in high-income countries, the discussions during the GCPCC were fuelled with insights from participants representing 29 countries worldwide.

Further fields related to person-centred care

We regard the development of person-centred care, driven by partnerships around what matters for the other, as one promising and necessary route towards meeting the current, as well as upcoming, demographic and social challenges. Here we relate this development to a foundation in human rights, antidiscrimination and inclusive, democratic strategies. Thus, it is a societal issue and the transition is not narrowly delimited to health care but also inclusive of planetary, as well as human health. Faltering health, illness, suffering and loss diminish a person's strength and prevent them from voicing their needs, making vulnerable and disadvantaged groups invisible. Allowing the patient to voice their needs is a foundational driver for person-centred care and related to equality, equity and sustainability. The preservation of dignity, respect for integrity, capability and agency are at the core of person-centred care.

Considering the aim of the initiative and international demographic trends such as population growth and ageing, urbanization and international migration, urgent action is needed in terms of attending to people's healthcare demands and the demands of society at large. For instance, looking at population growth and ageing, the demographics differ widely between countries, some growing fast with high birth rates, while others have low birth rates, aging populations and may even be starting to shrink. Despite these differences, the major trend is for lower birth rates, smaller families and longer lives. And in high-income countries, despite being provided with the conditions for successful aging and treatments, a large percentage of the population lives with faltering health due to long-term conditions that threaten their quality of life. In the later stages of life and at end of life, most populations live with increasing dependency on others and decreasing functionality, and thus require care and support. Indeed, people of all ages struggle with poor health for a variety of reasons, including mental health problems. The related challenges include healthcare cost acceleration, as well as a diminished healthcare workforce challenged with transforming healthcare for population needs of tomorrow.

For these reasons, the micro-meso-macro interrelationships of person-centred care come to the fore. The approach and system of care need to span and strive for congruency between the point of care, healthcare service and organisation, as well as high-level healthcare decision-making and policy. Within these societal and cultural movements, person-centred care also has a place in the development of digitalisation, precision health and similar complex developments that are promising, although may also include unintended consequences for people's health.

Looking at these larger global and societal trends, we will now consider some areas of significance relating to the knowledge of person-centred care in a future state of the science initiative.

*G*lobally, within and between countries, health inequalities exist based on *gender and other intersecting factors*, such as educational level, income and ethnicity. Person-centred practices, organisations and systems also require awareness of societal and international movements that go in various and also opposite directions, such as *anti-gender, racism, oppression, violence and crime*. If and how person-centred care is to battle with such inequities is an important question to pursue, involving multidimensional governance.

It is also well known that *self-care activities* such as proper nutrition, exercise and promotion of mental health can lower the risk of the chronic diseases that are major drivers of healthcare costs today. If people can manage minor health issues themselves or with support from family carers and communities, it frees healthcare resources. When people are knowledgeable about their health they can also engage more meaningfully in discussions with health professionals, resulting in improved outcomes through person-centred care. *Support for family carers* also comes with inequities. Again, gender and intersecting factors limit what health habits are available to a person and their possibilities for self-care and informal care.

Connected to the demographic trend of *international migration*, the need for health care to incorporate a variety of perspectives on health and illness must be understood and developed further. As we see it, the foundation and applicability of person-centred care could largely be strengthened by including non-western cultural norms, understandings and philosophies that emphasize interconnectedness and relationality. Sacredness and environmental connection could also be incorporated, as well as perspectives on planetary health.

We are immersed in a planetary crisis, with escalating climate change and rapid loss of biodiversity. *The environment*, which is crucial to human health and life, is threatened. Human-generated emissions of greenhouse gases and toxic substances in water, air and land have led to deteriorating habitats on Earth, and the healthcare industry is not free from culpability in this regard. How the ethics underlying person-centred care might be extended to accountability towards nature and non-humans in this Anthropocene age warrants further exploration.

Epistemological and methodological considerations must also be factored into person-centred care knowledge. As emphasised in previous chapters, practice-based wisdom and co-creation of knowledge are at the core of person-centred care. At the same time, documentation of PCC effects and efficacy, as well as its organisations and systems, is needed to inform equity and higher-level decision-making. Empirical person-centred care research is strongly marked by underlying assumptions of homogeneity in samples and populations, yet theoretical assumptions emphasise the uniqueness of people. Thus, the idea that people are heterogeneous and diverse is actually a core idea in person-centred care. Nevertheless, evaluations of, for example, person-centred care interventions primarily report results in terms of the sample average, and qualitative data similarly reports themes and categories that apply for whole samples. Knowledge of similarities and differences within samples and populations as related to person-centred care needs to be synthesised, with explication of related gaps.

Another important area is *the higher education of future health professionals*. We can expect that academic training will undergo a transformation in years to come, in order to adapt to demographic and societal trends, as well as a generational shift and fast technological development. In this process, which presents new challenges and possibilities, we need to make sure that person-centredness is comprehensively taught as well as evaluated, and includes knowing what and knowing how, as well as practical wisdom to act sensitively in situations. Meanwhile, current research points towards vagueness and variability in the person centred curricula.

The growing demand for healthcare and social welfare services, driven by an ageing population and the increasing prevalence of chronic diseases, presents us with an overarching challenge: *a workforce shortage*. In the years ahead, there will be an insufficient number of healthcare professionals to meet the demand, both in terms of healthcare and social welfare. This shortage presents a considerable challenge to maintaining standards of care. As the number of health professionals decline, the pressure on existing personnel intensifies, which may ultimately affect the quality and accessibility of equitable care. It is therefore time to incorporate solutions that expand healthcare services *beyond traditional models*. First, we need to implement a person-centred approach to health and care that puts people's self-care and informal care by family carers and communities at the fore. This will lead to systemic implementation of precision health and person-centred integrated care, redefining healthcare services to optimize the collaborative, person-centred care approaches. By addressing such challenges proactively, our healthcare system can be better designed to be resilient, equitable and sustainable.

An older population also presents new opportunities, such as *multigenerational workforces*. However, this requires support for lifelong learning and creating work opportunities for older people who would like to continue to work. Since women typically live longer than men, healthcare needs specific to women and social support related to easing caregiving burdens are of importance for person-centred care.

The capacities of patients, family carers and the public can be utilised in the creation of sustainable healthcare systems related to, for example, resource shortages, making it crucial to synthesise knowledge in terms of how to design services that are meaningful and adapted to the needs of individuals and populations. How practices for *public involvement and engagement* might overlap with person-centred care and share common ground needs further exploration.

There is also an increasing need to synthesise person-centred care governance and health systems to further develop innovative governance models that place people at the centre. There is also a need to understand how the current evidence of person-centred care is adapted and developed into governance structures. Such a shift requires a departure from traditional, top-down governance and the development of flexible, responsive frameworks that can adapt to diverse and dynamic health contexts. Research on person-centred governance is essential to explore how, for example, health policies and systems can be more effectively co-designed with communities and stakeholders. By investigating methods to include patient and public perspectives, commercial, environmental and social determinants of health, and community values in governance, frameworks can be developed that support more equitable, sustainable, and effective healthcare systems. Such research should focus on strategies to balance scientific and technical advancements with human needs, addressing challenges like data privacy, equitable access, and the avoidance of biases in precision health technology and

AI. We suggest that policy labs are interesting to include in such person-centred governance strategies. By creating experimental spaces where new governance models can be trialled, policy labs allow for the iterative design, testing, and refinement of strategies in controlled environments. In such labs, policymakers, researchers and public representatives can collaboratively explore and assess the impact of various governance approaches, identifying those that most effectively align with person-centred goals. Through real-world simulations, feedback loops and data-driven insights, policy labs can refine governance models and generate evidence on what works best for different populations and settings.

Healthcare funding models and how these impact on the practice of person-centred care need further exploration. Funding models based on functional needs, medical disease classifications, health care activities and/or interventions need to be critically examined as to how they influence public involvement, shared decision making, person-centred care and partnerships between health care representatives and people in need of care, as well as the commercial, social and environmental determinants of health. Funding models guide decisions at every level in health care and are generally allocated based on medical interventions and activities, hence need to go beyond reactivity and become more proactive regarding both prevention and health promotion. In times of retracting financial envelopes and a decreasing healthcare workforce, a long term commitment to strategic investment is needed to understand which financial models (including incentives models) are most influential to support and empower equitable and sustainable person-centred healthcare. We also need to understand how these models can be rapidly implemented to scale for people in need of care so that they really become partners in their own health care and social welfare.

Next steps

To further support the transition to person-centred care, a range of initiatives are needed on governance, organisation and practice levels. Hence, for state of the science initiatives, the overall fields of importance could be stated as *micro-meso-macro interrelationships*. This is broad indeed, requiring us to tentatively point out a few of the relevant areas within such a scope. These are meant as triggers for further development of person-centred care knowledge, and to clarify 'what is known', what is inconsistent in the knowledge and what the knowledge gaps are:

- Similarities and differences in effective interventions at the point of care, and what constitutes relevant contextual adaptations

- Similarities and differences in effective knowledge translation strategies at micro, meso and macro levels
- Precision health and digitalisation
- Healthcare workforce as related to governance and funding of health care
- Interrelations between health systems, governance, funding, workforce and practices
- Interdisciplinary collaborative knowledge and interprofessional person-centred care practices
- Consequences of heterogeneous and diverse populations and their influence on governance, organisation and practices to support people's health
- Leadership, learning, education, and policy
- Patient and public involvement in healthcare organisational decision-making at different levels, as related to research-based knowledge about living with health, illness, suffering and loss
- Interplay between professional health care and informal care in communities and civil society

We hope this report provides food for thought to further comprehend the state of the science in person-centred care. This report is to be regarded as a work in progress – there is considerable knowledge to synthesise and generate, and this includes unpacking the most important knowledge gaps to inform further development of the field. There are significant initiatives for doing so around the globe. One of these is the second *Global Conference on Person-Centred Care* that will take place in Gothenburg in May 2026. We welcome everyone to contribute with submissions and, of course, to participate and critically dialogue person-centred care with colleagues from around the globe. Together, we can make a difference!

7 Appendix

7.1 Programme for the sessions at the 1st GCPCC forming the basis for this report

GCPCC
13-16 MAY 2024
GOTHENBURG
SWEDEN

Striving forward: Towards the State of Science in Person-Centred Care

The knowledge field of person-centred care is extensive and proliferating and marked by a combination of empirically grounded knowledge and major theoretical frameworks. As part of the GCPCC, there will be a special session Towards the State of Science in Person-Centred Care. This special session will span the whole afternoon of Wednesday 15th May.

Key scholars in the field of person-centred care will meet at the *Global Conference on Person-Centred Care*, the GCPCC, which creates opportunities for taking steps toward summarising the state of science in the knowledge field of person-centred care. The goal is to provide an overview of the current knowledge of 'person-centred care in a generic sense' that critically picturises where theoretical and empirically informed advancement has reached so far. The overall purpose of the initiative is to provide a benchmark to further the scientific progress. The step taken at the GCPCC is to be regarded a first one, which undoubtedly needs to be followed up. This means, for example, that identifying knowledge gaps will most likely be completed in following steps. Following the special session, a report will be published based on the discussions held.

Session objectives

To provide an overview of the state of person-centred care pertaining to core theoretical foundations, and modes and strategies for translating person-centred care into practice, guided by three overall questions:

- What is the established knowledge?
- What remains to be known, or is inconclusive/inconsistent knowledge?
- What further scientific work is needed to move the state of science forward?

Outline for the session

I. Brief presentations of influential frameworks of person-centred care - 60 min

1. The development of person-centred care in relation to broader societal movements, Axel Wolf
2. Person-centred care with a foundation in ethics, Inger Ekman
3. Person-centred practice, Brendan McCormack
4. Person-centred care, Maria Santana
5. Integrated person-centred care, Viktoria Stein
6. Commentary: David Edvardsson

II. Reviews informing current knowledge about person-centred care[13] – 60 min

1. Emma Forsgren. Mapping the concept of centeredness in healthcare research: a scooping review (ID 155)
2. Salma Pardhan. Costs and associated health outcomes of person-centred interventions: a systematic review (ID 090)
3. Vaibhav Tyagi. The state of science in cardio-vascular person-centred practice: a systematic review (ID 167)
4. Zahra Ebrahimi. Key components in implementation of person-centred care for older people in out-of-hospital settings: a systematic review (ID 036)
5. C Anker-Hansen. The interplay of leadership dynamics and person-centred practice in nursing homes (ID 106)
6. Commentary: David Edvardsson
7. Introduction to the workshop part of the session: goals, objectives and short presentation of participants in the groups for the final part of the session – 15 min

III. Group discussions aiming to sum up, analyse and critique according to the objective stated above – 60 min

There will be a maximum of 12 groups, and two groups discussing the same question. The structure for the group discussions is:

- Core theoretical foundations
  1. What are the core assumptions/premises for person-centred care: similarities and differences? What remains to be known or is inconclusive/inconsistent? (Group 1 & 7)

---

[13] These presentations were based on abstracts submitted for presentation at the GCPCC.

   2. What are the major concepts and attributes/features of person-centred care? What remains to be known or is inconclusive/inconsistent (Group 2 & 8)
- Modes and strategies for translating person-centred care into practice
   3. What are the primary strategies and principles for person-centred care knowledge translation? What remains to be known or is inconclusive/inconsistent? (Group 3 & 9)
   4. What are the prerequisites, mediators (barriers and facilitators) and expected outcomes for person-centred care knowledge translation? What remains to be known or is inconclusive/inconsistent? (Group 4 & 10)
   5. What are the micro – meso – macro links and interrelations for person-centred care knowledge translation? What remains to be known or is inconclusive/inconsistent? (Group 5 & 11)
   6. What are the fields/areas with strong examples for practice implementation – fields with potential to act as benchmarking partners? What generic knowledge about practice implementation can be identified in such fields? What remains to be known or is inconclusive/inconsistent? (Group 6 & 12)

In each of the groups there will be one designated participant to coordinate the discussion and one to take notes.

The first part (I) will take place in a large lecture hall (cinema seating), since we assume presentations of the major frameworks will attract several participants at the conference. The other parts (II and III) will take place in a workshop room, where the participants will sit in groups with round tables.

Based on the whole session, including the group discussions, a written report on “towards the state of the science of person-centred care” will be completed following the GCPCC; all presenters, commentators, chairs and note takers for the group discussions will be invited as co-authors. To facilitate the report, we will explore possibilities for the sessions to be recorded. The tentative plan is that this report will have the same overall structure as the session outline described above. For the first part, presenting the major frameworks, we can offer you a choice of contributing with your own manuscript or having your framework described, based on the recording of your presentation. We can decide on this later.

7.2 Suggested readings as related to the frameworks

The following references were available to the session participants in advance and provided the foundation for this report and especially the workshop discussions presented in Chapter 6.

Person-centred care with a foundation in ethics, Inger Ekman

Britten, N., Ekman, I., Naldemirci, Ö., Javinger, M., Hedman, H., & Wolf, A. (2020). Learning from Gothenburg model of person centred healthcare. *BMJ*, 370. https://doi.org/10.1136/bmj.m2738.

Ekman, I. (2022). Practising the ethics of person-centred care balancing ethical conviction and moral obligations. *Nursing Philosophy*, *23*(3), e12382. https://doi.org/10.1111/nup.12382.

Ekman, I., Swedberg, K., Taft, C., Lindseth, A., Norberg, A., Bergbom, I., Brink, E., Carlsson, J., Johansson, I.-L., Kjellgren, K., Lidén, E., Öhlén, J., Olsson, L.-E., Rosen, H., Rydmark, M. & Stibrant Sunnerhagen, K., for the University of Gothenburg Centre for Person-Centred Care (GPCC). 2011). Person-centered care – Ready for prime time. *European Journal of Cardiovascular Nursing*, *10*, 248-251. https://doi.org/10.1016/j.ejcnurse.2011.06.008.

Person-centred practice, Brendan McCormack

McCormack, B. (2020) The Person-centred Nursing and Person-centred Practice Frameworks: from conceptual development to programmatic impact. *Nursing Standard – RCN Fellows Special Supplement 35*(10),86–89. https://doi.org/10.7748/ns.35.10.86.s40.

McCormack, B., McCance, T., Martin, S., McMillan, A., Bulley, C. (2021) *Fundamentals of Person-centred Healthcare Practice*. Wiley. Available here

Person-centred care, Maria Santana

Manalili, K., Scott, C. M., O'Beirne, M., Hemmelgarn, B. R., & Santana, M. J.
(2022). Informing the implementation and use of person-centred quality indicators: A mixed methods study on the readiness, barriers and facilitators to

implementation in Canada. *BMJ Open*, *12*, e060441. https://doi.org/10.1136/bmjopen-2021-060441.

Santana, M. J., Ahmed, S., Lorenzetti, D. L., Jolley, R. J., Manalilli, K., Zelinsky, S., Quan, H. & Lu, M. (2019). Measuring patient-centred system performance: A scoping review of patient-centred care quality indicators. *BMJ Open* (1), e023596. https://doi.org/10.1136/bmjopen-2018-023596.

Manalilli, K., Siad, F. M., Antonio, M., Lashewicz, B. & Santana, M. J. (2021). Codesigning person-centred quality indicators with diverse communities: A qualitative patient engagement study. *Health Expectations, 25*(5), 2188–2202. https://doi.org/10.1111/hex.13388.

Santana, M. J., Manalilli, K., Zelinsky, S., Brien, S., Gibbons, E., King, J., Frank, L., Wallström, S., Fairie, P., Leeb, K., Quan, H. & Sawatzky, R. (2020). Improving the quality of person-centred healthcare from the patient perspective: development of person- centred quality indicators. *BMJ Open 10*,e037323. https://doi.org/10.1136/bmjopen-2020-037323

Ahmed, S., Djurkovic, A., Manalilli, K., Sahota, B. & Santana, M. J. (2019). A qualitative study on measuring patient-centered care: Perspectives from clinician-scientists and quality improvement experts. *Health Science Reports*, *2*(12), e140. https://doi.org/10.1002/hsr2.140.

Doktorchik, C., Manalilli, K., Jolley, R., Gibbons, E., Lu, M., Quan, H. & Santana, M. J. (2018). Identifying Canadian patient-centred care measurement practices and quality indicators: A survey. *CMAJ Open 6*(4), E643-E650. https://doi.org/10.9778/cmajo.20170143

Ahmed, S., Siad, F. M., Manalilli, K., Lorenzetti, D. L., Barbosa, T., Lantion, V., Lu, M., Quan, H. & Santana, M. J. (2018). How to measure cultural competence when evaluating patient-centred care: A scoping review. *BMJ Open 8*, e021525. https://doi.org/10.1136/bmjopen-2018-021525

Santana, M. J., Manalilli, K., Jolley, R. J., Zelinsky, S., Quan, H. & Lu, M. (2018). How to practice person-centred care: A conceptual framework. *Health Expectations. 21*(2),429–40. https://doi.org/10.1111/hex.12640.

GOTHENBURG STUDIES IN PERSON-CENTRED CARE
ISSN 3035-7209 (print)
ISSN 3035-7217 (online)
Editor: Eric Carlström

Subscriptions to the series or orders for individual copies sent to:
Acta Universitatis Gothoburgensis
Box 222, 405 30 Göteborg, Sweden
acta@ub.gu.se

Earlier publications:

1. AXEL WOLF & JOAKIM ÖHLÉN (Eds).
The first global conference on person-centred care: Knowledge(s) and innovations for health in changing societies: Abstract book. Göteborg, 2024.

2. AXEL WOLF, EMMA FORSGREN, IDA BJÖRKMAN, DAVID EDVARDSSON & JOAKIM ÖHLÉN (Eds). *Towards state of the science in person-centred care.* Göteborg, 2024.

This report provides an overview of the current knowledge of person-centred care and critically illustrates where the theoretical and empirically formed advancement in the field has reached so far. Presentations of brief overviews of four theoretical frameworks and five research literature reviews as related to person-centred care are included as well as commentaries from an international panel who participated in workshops during the first Global Conference on Person-Centred Care (GCPCC) held in Gothenburg, Sweden, in May 2024.

The Gothenburg Series in Person-Centred Care is issued by the University of Gothenburg Centre for Person-Centred Care (GPCC), a Swedish centre of excellence in person-centred care. GPCC conducts clinical and applied interdisciplinary research, and develops methods for implementing and evaluating person-centred care in practice. Its overall vision is sustainable health through sustainable care: to prevent and reduce suffering, and strengthen the efficiency of health care through person-centred care.

ISBN 978-91-7963-201-4

9789179632014