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DISCUSSION

Towards Person-Centred Care: Using the Capability Approach Together with the International Classification of Functioning, Disability and Health

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KEYWORDS Person-centred care; wellbeing; disability; health care; capability approach

Introduction

The concept of person-centred care is not new. The person-centred approach was first pioneered by Rogers (1951) and later developed in the context of healthcare by psychiatrist George Engel, who proposed the biopsychosocial model of health as an alternative to the biomedical model to better understand health and its determinants (Engel 1977). In the biopsychosocial model of health, health is understood broadly as being influenced by a variety of factors, including biological factors (e.g. genetics, brain chemistry), psychological factors (e.g. thoughts, emotions, behaviours), and social factors (e.g. multidimensional poverty, discrimination). With this holistic understanding of health, healthcare moves away from being purely medical and paternalistic towards being wholistic and centred on the needs and preferences of the patient, their family and carers. "The philosophy underpinning patient-centred care seems to have its roots in virtue ethics, with the ultimate aim being Aristotelian eudaimonia (flourishing)" (Latimer, Roscamp, and Papanikitas 2017, 425) capturing, from a capability approach perspective, not an emotional experience but more broadly the sense of a complete and fulfilled life.

Since the early 2000s, different countries and institutions around the world have embraced the notion of person-centred care. An enabling environment for person-centred care requires resources towards essential services that affect health and wellbeing, including education, social protection, and employment services. Policies and programmes need to be person-centred across sectors to ensure that resources that reflect people's needs and priorities are available (Onyejekwe 2023). The 2006 United Nations Convention on the Rights of Persons with Disabilities (CRPD), ratified by 192 countries, supports person-

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centred care by establishing the rights of persons with disabilities to live in their communities and access care, such as healthcare (Article 25) and rehabilitation care (Article 26). Person-centred care is relevant to Sustainable Development Goal (SDG) 3 to promote health and wellbeing for all people. It is also relevant to SDGs and sectors other than health. Another example is given by the UK National Health Service which, in 2000, included patient-centred care as part of its core principles.

Yet, putting person-centred care into practice remains challenging and may not always be achieved, even when endorsed in principle (Latimer, Roscamp, and Papanikitas 2017). Its implementation is particularly difficult, especially in the context of multiple global crises that limit resources, including climate change, armed conflicts, and a post-pandemic context. Moreover, in the aftermath of the COVID-19 pandemic, it is important to drive faster progress to deliver person-centred care.

In this Policy Forum, we explore *how* the joint use of the International Classification of Functioning, Disability and Health (ICF) and the Capability Approach (CA) (van der Veen et al. 2022) can inform framing policy and practice towards person-centred care, whether in its design, implementation or evaluation. Care is understood broadly and includes various types of care such as healthcare (primary care, specialised healthcare such as rehabilitation services) or employment services. Care is specifically considered for individuals with health conditions or disabilities at various life stages and in diverse contexts.

What is the ICF and How Has it Been Used?

The ICF was developed by the World Health Organization (WHO) as both a conceptual framework and a classification for analysing the consequences of health conditions at both individual and population levels (WHO 2001). The ICF model was based on the biopsychosocial model of health, providing a structured approach to framing and classifying the consequences of health conditions (WHO 2001). It is a revision of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) and was developed by WHO as part of its mandate to collect information about the health of populations worldwide.

The ICF model starts with a health condition (disorder or disease) that within contextual factors gives rise to impairments, activity limitations and/or participation restrictions. Contextual factors refer to the entire background of an individual's life. It includes personal factors: gender, age, coping styles, social background, education, profession, and behavioural patterns. Contextual factors also include environmental factors. They make up the "physical, social and attitudinal environment in which people live and conduct their lives" (WHO 2001). An impairment, using WHO's (2001) definition, is defined as

a "problem in bodily function or structure as a significant deviation or loss". An activity is the execution of a task or action by an individual. Participation is understood in terms of involvement in a life situation. Activity and participation domains include learning and applying knowledge, education, remunerative employment and economic self-sufficiency.

Functioning and disability are umbrella terms, one the mirror image of the other. Functioning covers body functions and structures, activities and participation, while disability refers to impairments, activity limitations and participation restrictions.

In addition to being a conceptual model, the ICF is a classification used by professionals to frame the collection of salient data on the lived experience of health conditions for policy, programmes (e.g. eligibility to benefit) or clinical practice. It provides lists of health conditions, impairments, activity limitations and participation restrictions that professionals have used to measure outcomes.

The ICF has been increasingly used in healthcare research in the past two decades, in rehabilitation and more recently in epidemiology in global north contexts (Stojic et al. 2024). Stojic et al. (2024) note that "The increasing application of the ICF in rehabilitation research underscores its value in developing comprehensive, person-centred care plans."

In addition, the ICF has been used to structure data collection regarding the consequences of health conditions and disability. WHO has developed specific survey instruments based on the ICF such as the World Health Organization Disability Assessment Schedule II (WHODASII) and the Model Disability Survey.

Finally, an analysis of 20 years of ICF use revealed that it is primarily applied in clinical practice, policy development, social policy and education, serving as a biopsychosocial framework where implemented (Leonardi et al. 2022). Thus, the ICF has been used for a variety of purposes, to describe but also to explain and analyse human functioning as well as to frame and implement a range of policies and programmes in healthcare and beyond.

ICF, the CA and Person-Centred Care

There is a growing literature comparing the ICF and the CA (e.g. Trani et al. 2011; Bickenbach 2014; Mitra 2014; Mitra 2018; van der Veen et al. 2022). For instance, while introducing the human development model of disability, health and wellbeing, an application of the CA to disability, Mitra (2018) notes that, compared to the ICF, the CA can enlarge our understanding of the disablement process by highlighting the role of resources and conversion factors, by incorporating agency and by including capabilities and functionings as metric of wellbeing. It should be noted that the term "functioning" has different meanings in the ICF model and the CA. In the ICF, functioning (singular) refers to body functions and structures as well as activities and participation in a specified range of life domains (e.g. education, selfcare and

work). In the CA, functionings (plural) represent the achieved beings and doings that people value (capabilities) and are not pre-specified (Sen 2009).

Relatedly, concerns have been raised about the extent to which the ICF is truly person-centred from the perspective of the CA (e.g. Mitra and Shakespeare 2019; Trani et al. 2011, van der Veen et al. 2022). First, there are concerns about the functioning that is captured as part of the ICF. Mitra and Shakespeare (2019) argue that the emphasis on activities and participation in the ICF seems to be in tension with person-centred care. The ICF classification to assess functioning and how this may be affected by health conditions is based on a notion of functioning related to body functions, activities and participation. If the ICF model is adopted, say to frame an intervention providing physical rehabilitation services to persons who had polio, then the resulting activities and participations would be measured. Mitra and Shakespeare (2019) ask: "are activities and participations all that lives are made of? Where would states of being fit (e.g. being well nourished)? Activities and participation supplemented by a more holistic concept, such as capabilities and functionings in the CA". Moreover, functioning based on the ICF is generally captured by medical and paramedical professionals to frame their assessments of patients and to organise and store information on patients' outcomes. Thus, it provides assessments of functioning that are largely influenced by the professionals' views and not by the person's views and perceptions (van der Veen et al. 2022).

Second, it has been noted that the ICF does not include personal goals and agency (e.g. Bickenbach 2014; Mitra and Shakespeare 2019, van der Veen et al. 2022). Yet, in person-centred care, there is a need to account for whether an individual is able to act, participate or live on behalf of what matters to them. What if the activities and participations under consideration in the ICF are not those valued by the individual (Mitra and Shakespeare 2019)? In other words, a limitation is that the ICF does not explicitly incorporate choice, and its activities and participation domains may not reflect the values and aspirations of individuals and communities. In contrast, the CA is centred on the expansion of people's opportunities to be or do what they value and have reason to value (their capabilities) and people's ability to be authors of their own lives, the ability of people to help themselves and to influence the world i.e. their agency (Sen 2009). Therefore, the ICF and the CA can complement each other.

This Policy Forum explores how using the ICF jointly with the CA in policy and practice may bring into care intervention capabilities as well as agency to make them person-centred.

Policy Forum Essays

This Policy Forum consists of four essays that provide reflections on ways whereby the ICF and the CA have been used in policies and programmes that aim to provide person-centred care in varied contexts.

van der Veen et al. argue that healthcare interventions framed within the ICF can become more person-centred by infusing agency through the CA. van der Veen et al. explain how the ICF and the CA can be combined at different levels of the Pyramid of Care (individuals, communities, professionals, organisations, systems and the earth) in order to make healthcare policies and practices more person-centred. More specifically, individuals make their own assessments of their body functions, activities and participation as per the ICF nest to of professionals making such assessments. In addition, individuals develop their own goals and plans of action based on what they value. The authors provide the example of an e-health application used in the BigMove intervention in the Netherlands in which people can asess their functioning. This application includes all categories of body functions, activities and participation of the ICF classification (e.g. working, going to a place of worship) but is for the use of patients who self-report their progress, and their goals and develop action plans to achieve these goals.

Similarly, Arciprete et al deploy a digital tool, VINIL (Valutazione Integrata per l'Inclusione Lavorativa), which integrates both the ICF classification with the CA to deliver a person-centred assessment of employability among persons with disabilities in Tuscany, Italy. As noted by Arciprete et al "the challenge for employability assessment lies in implementing a genuinely person-centred approach that accounts not only for impairments, functional limitations, and environmental barriers but also for capacities, values, aspirations, and agency". This paper argues, using VINIL as a case study, that integrating the ICF and the CA provides a robust framework for addressing this challenge. Developed through a participatory process involving over 100 participants, VINIL was utilised to assess the employability of 2025 persons with disabilities. It shows that using an assessment based on both the ICF and the CA can significantly improve the prospects of individuals with disability in obtaining and maintaining meaningful employment. Additionally, by generating valuable aggregated data, the VINIL tool provided policymakers with crucial insights to inform more effective and inclusive employment policies.

Trani et al conducted a participatory child-centred pedagogy intervention in primary rural schools of Afghanistan and Pakistan. The intervention was framed conceptually using the CA while it used a disability measure grounded in the ICF to disaggregate its results by disability status. The intervention was designed with a focus on what the children and the community value as part of its objectives, including the children's capacity to aspire. Trani et al use the Child Functioning Module developed by UNICEF and the Washington Group to measure disability among children aged 5–17 years and disaggregate outcomes by disability status. This module is based on the ICF, to pick relevant domains of body functions, activities and participation to identify children with disabilities.

In the fourth essay, Riddle argues that the ICF should be used together with the CA to allow agency when formulating policy about end-of-life options and

care. Despite death, and the subsequent loss of functioning emerging from VSED, passive euthanasia, and assisted dying, the respect for agency emerging from the CA suggests that such practices ought to be permitted and solidified through policy commitments. Riddle concludes that professionals should have an obligation (and receive training) to make room for a patient's agency in decisions related to end of life.

Conclusion and Future Directions

Countries around the world and global policy frameworks, such as the CRPD and the SDGs, support the notion of person-centred care. Yet, delivering person-centred care through policy and practice is challenging, especially during crises. This Policy Forum aims to consider *how* the joint use of the ICF and the CA can help frame policy and practice towards person-centred care.

First, this Policy Forum points to the importance of a participatory approach to person-centred care interventions. Arciprete et al. and Trani et al, show how the CA can be used to develop interventions with the involvement of relevant communities in terms of employment services and pedagogy respectively. The participatory approach led to the designing of interventions that responded to the needs of the communities in line with person-centred care.

Second, this Policy Forum essay points out how the ICF provides a valuable framework for collecting information on the consequences of health conditions, which can enhance policy evaluations. Trani et al use the ICF to disaggregate indicators of capabilities and functionings by disability status. Human diversity is at the core of the CA and care interventions grounded in the CA need to be assessed for potential varying effects across groups and the ICF can support assessments by disability status. In addition, three of the four papers use the ICF to structure data collection. Trani et al use the child functioning module, a tool grounded in the ICF, to identify children with disabilities and implement an impact evaluation disaggregated by disability status. Arciprete et al and van der Veen et al stress the importance of moving away from the professionals making assessments as traditionally done with the ICF to the person making their own assessment.

Third, all forum contributions stress the imperative to consider how person-centred care interventions are conceptually framed and, in particular, the need to move away from a purely biopsychosocial model of disability such as the ICF and to transition towards a framework where agency is at the core, such as the CA. It is important for research to analyse the conceptual frameworks that underlie person-centred care policies and practices and inform transitions towards constructs centred on the agency. Agency, as commitment, is closely connected to person-centred care in giving the possibility to design tailored actions for and with the person. At the same time, this must be balanced as

there is a risk of consumerism with excessive use of personal agency against doctors/professional agency care (Latimer, Roscamp, and Papanikitas 2017).

There are other person-centred care policies and practices that combine the CA and the ICF that could not be described in this Policy Forum. For example, the *Project of Life* is a policy where the ICF can inform the individual project of life when the process is combined with the CA through a participatory approach focussing on agency to deliver person-centred care to persons with disabilities. This process involves the whole human being (the body, the psyche and the spirit). The aim is to elaborate a project (and not a pre-defined plan) where the beneficiary is the main decision-maker and actor, supported by professionals and other persons, throughout the empowerment process (e.g. Barbuto, Biggeri, and Griffo 2011). This growing literature together with this Policy Forum shows that while the ICF provides a valuable framework and classification regarding the consequences of health conditions, it does not fully capture a person's needs, values, and preferences – elements fundamental to person-centred.

Therefore, if used for policymaking, it needs to be complemented by an agency-oriented approach such as the CA. The ICF should be revised or accompanied by implementation guidelines where the agency is presented as being at its core for human flourishing.

In the context of multiple global crises that limit resources dedicated to care, there is an urgent need to accelerate the delivery of person-centred care with a central focus on agency. The various stakeholders involved in person-centred care (e.g. institutions, professionals) need to protect and leverage human agency.

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Disclosure Statement

No potential conflict of interest was reported by the authors.

Notes on Contributors

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Sophie Mitra is a professor of economics at Fordham University. Her research agenda has documented economic insecurity and evaluated policies that try to reduce it, in particular in relation to disability, aging and health. She is the founder of the Disability Data Initiative and the author of Disability, Health and Human Development (2018), in which she proposed the human development model disability, health and wellbeing based on the capability approach.

Sabina van der Veen is a postdoctoral researcher at Leiden University, Faculty of Humanities. Her research focuses on the application of the International Classification of Functioning, Disability, and Health (ICF) and the Capability Approach in diverse care settings. Before her current position, she was a researcher and teacher at Amsterdam UMC, coordinated the EIP-Active Healthy Ageing Amsterdam Metropolitan Area, and advised on healthcare innovation policy. She co-founded the National Dialogue Community Empowerment and currently coordinates the HDCA Health & Disability thematic group. She began her career as a (paediatric) physical therapist.

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