Same *and* Different?

Perspectives on the Introduction of Person-Centred Care as Standard Healthcare

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Abstract

This thesis examines a collection of cases and situations where efforts are being made to combine and unify the concerns of person-centred care, standardization and evidence-based medicine. Person-centred care is commonly associated with efforts to improve the quality of healthcare by catering for variation and difference while evidence-based medicine and standardized guidelines aim to assure quality by reducing difference and variation. Therefore, this thesis aims to investigate the paradoxes and tensions emerging as person-centred care is introduced as standard healthcare, and the actions taken by healthcare professionals to secure this healthcare reform in practice. The analysis builds on interviews with researchers working at a research centre where a particular standardized model of person-centred care has been developed; interviews with healthcare professionals working with and introducing this standardized model; observations of healthcare professionals applying this standardized model in practice, and related documents and written materials. The thesis builds on a practice oriented approach to person-centred care and adopts a material semiotic sensibility as a theoretical foundation. This approach enables detailed analysis of the messy, relational socio-material practices of person-centred care in action. Using the notions of tinkering and articulation work, the thesis extends the basic lessons of material semiotics by underscoring the importance of reciprocity - interrogating how inventive practices act back on and reshape tools, technologies and standards of person-centred care.

Empirically the thesis encompasses four studies. Paper I examines the mundane technologies of person-centred care, the scripts and values inscribed in these technologies and the tinkering needed to balance and bring together potentially contrasting values in practice. Paper II investigates how person-centred care and evidence-based medicine are interwoven in practice and the tensions that emerge when a randomized controlled trial is used to evaluate person-centred care. Paper III draws on the notions of articulation work and invisible work to analyse the efforts involved in sustaining a particular standardized framework of person-centred care. Paper IV identifies the tenacious assumptions embedded in a standardized model of person-centred care and the challenges emerging when this model is introduced in diverse settings.

Based on these studies I argue that while person-centred care is often advocated as the anti-thesis to standardized biomedicine this relationship is more complex. The studies in this thesis address attempts to develop a model of healthcare that is at once the *same* for all patients, yet also *different* by catering to each individual patient as a unique person. However, modelling care in this way is not without its challenges. One of the foremost challenges of making care recognizing the patient as a person into standard healthcare concerns how this person is actually imagined and enacted. By insisting on particular routines to be followed and specific values to be recognized particular versions of person-centred care risk embedding problematic assumptions of their own. These assumptions are very similar to those it aims to move beyond in the first place. The standardized model of person-centred care, as well as the tensions and challenges it gives rise to, are negotiated and managed in a variety of ways. Caregivers are obliged to make adaptions, translations and become creative mediators in order to enable the standardized model of person-centred care to hold together. They also have to coordinate different tasks, perform complex activities for which they have little prior training, and creatively interpret incomplete instructions in order to compensate for shortfalls in information. However, the thesis concludes that things could be otherwise if person-centred care was able to learn from material semiotics. Instead of conceiving person-centred care as something that has to be implemented and safeguarded in practice, an alternative vision would be to develop person-centred care in its local organizational complexity and thereby transform it from being something ready-made, which care professionals have to adhere to, to something that is an outcome of experimental interventions.

Key words: person-centred care, standardization, evidence-based medicine, material semiotics, practice oriented approach