
CONFERENCE ABSTRACT

Person-centered Parkinson's care Portrayed

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Thieme Stap¹, Jan-jurjen Koksma, Richard Grol, Roland Laan, Bastiaan Bloem, Marten Munneke

1: Radboudumc Health Academy, Netherlands

Introduction

Person-centered care (PCC) is at the center of integrated care. Research into this complex concept often leans towards reductionism, out of scientific convention, which encapsulates PCC in care figures ("I give my care-process a 7/10"), questionnaires, or overly structured interviews. As an alternative, we have developed a more open approach to scrutinizing PCC: a participatory, arts-based research design using photography.

Aims Objectives Theory or Methods

Together with people with Parkinson's (PwP) and their care professionals (from all kinds of disciplines), we have an in-depth conversation on PCC, while a photographer makes photographs of them and their (healthcare related) interactions. Both the photographic and interview materials are analyzed (using arts-based techniques and grounded research methodology), and then used to create an interview template for a second, individual interview with each participant at their home. There, we talk about the photographic material.

Highlights or Results or Key Findings

Together, these thick descriptions offer a 'richer' view of PCC and focus on how chronically ill people learn and co-create PCC together with their care professionals. We have obtained paradigmatic narratives of transformative moments. For instance, there is the story of Bob and Bas. Bas, a neurologist and a renowned care innovator, realized that this new environment and the time spent together there, offered insights that he could use to help Bob carry out his hobby better. And Bob realized that his Parkinson's seems to have made him even more creative, although he already had a creative occupation as an interior designer. Next to these narratives, our research has yielded an abundance of themes, such as "touch in a care relation", "how I want to be seen", "seeing the other", and so on.

Conclusions

We developed an uncommon, participatory arts-based approach to work together with PwP and their care professionals to obtain rich data. This approach yields a myriad of insights in PCC that

cannot be summarized in a single sentence. From those insights, we deduce design-principles for improving care practices as learning environments.

Implications for applicability/transferability sustainability and limitations

The design principles are directly used in care innovations (i.e. the PRIME-PD study). Adjoining that, the research is used in educational settings, for students and vocational training alike. The applicability and limitations of using photography as a research method have been written about in a bookchapter, coming out early 2022.