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Conference Abstract

Patient narratives on person-centeredness in the integrated care context

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Abstract

Background: Person-centred care emphasises the benefits of a holistic, humanistic approach that puts patients first and at the centre of clinical care. Person-centeredness is also considered a core element of integrated care. Yet typologies of integrated care mainly describe how patients fit within services, rather than how services fit into the patient's world, and it is unclear how 'person-centeredness' is realized in integrated care.

Purpose and objectives: We aimed to explore patient narratives on person-centeredness in the integrated care context.

Method: We conducted a phenomenological, qualitative study, borrowing from Grounded Theory approach principles. The study included semi-structured interviews with 22 patients registered in the Northwest London Integrated Care Pilot.

Findings: We identified six theoretically-derived themes representing core 'ingredients' of person-centeredness in the integrated care context: "Holism", "Naming", "Heed", "Caring", "Continuity of care", and "Agency and Empowerment", all depicting patient assumptions on doctor and patient roles in an integrated care. We bring positive examples showing that when these needs are met, person-centeredness can make a whole difference for the patient, but also examples of loaded with emotional tone expressing deep frustration from encounters with health providers, and an experience of being 'unseen' and unheard. We describe how these six themes can portray a continuum between two conflicting experiences of 'Translucence' (being 'unseen', unheard) vs. having own unique physical and emotional 'Space' to be 'seen' and heard.

Conclusions: Integrated care models can benefit from incorporating person-centeredness as a core element. Such implementations apparently require deep attitudinal and cultural change in care models, on top of organizational changes.

Keywords

integrated care, patient centred-care, in-depth interviews, qualitative research, person-centred, patient empowerment
