
POSTER ABSTRACT

Interviewing persons-supported in an evaluation of individual person-centred care plan development for community-care services: practical methodological considerations

23rd International Conference on Integrated Care, Antwerp, Flanders, 22-24 May 2023

Brian Dunne¹, Gillian Young², Donnie Antony¹, Ruth Armstrong¹, Bridget Ryan²,
Shannon Sibbald², Yona Lunskey³, Leslie Meredith², Maria Mathews²

1: PHSS - Medical & Complex Care in Community, London, Ontario, Canada

2: Western University, London, Ontario, Canada

3: University of Toronto, Toronto, Ontario, Canada

Background: Person-centred care plans (PCPs) have been identified as a promising upstream intervention to address health inequities in the community-care population. Studies in primary care and long-term care have shown that a person-centred approach has the potential to reduce costly and preventable health service utilization, improve health outcomes, and improve person-supported and provider experiences. PHSS Medical and Complex Care in Community (hereafter PHSS) uses an individualized, person-centred, participatory model of care. PHSS creates PCPs through a series of discussions with the person-supported, and with input from family members, friends, staff, and community members. PCPs incorporate personal goals and support participation in activities that are meaningful to each person-supported. PCPs are annually reviewed and updated, and provide a road map to services and supports, with options tailored to individual needs and capacities. PHSS is a partner in the research project and has been involved in team meetings and all project decisions.

Objectives: As part of a larger project evaluating PCPs, we conducted interviews with person-supported by PHSS which includes individuals with physical and developmental disabilities and complex medical conditions that may pose challenges to conducting traditional qualitative interviews. We describe experiences of conducting interviews with persons-supported, and outline practical steps in gathering data from this population.

Methods: Using a descriptive qualitative design, we conducted semi-structured interviews with 13 persons-supported. PHSS staff acted as an intermediary to help recruit and consent participants and conduct interviews. Participants chose where interviews took place and whether or not staff was present. Interviews were conducted in person, took up to 30 minutes, were recorded, and transcribed verbatim for analysis. In each interview, we asked about: the process used to create PCPs; examples of how PCPs were tailored to the person-supported's goals; perceived benefits and challenges of carrying out the PCP on persons-supported, their families, and on staff; and supports/barriers that facilitate/hinder the individualized participatory process. We also gathered relevant demographic data to describe participants. Using correspondence from

the research ethics board, field notes (including notes from reflection journals), we outline practical steps in conducting interviews with vulnerable, often non-verbal participants.

Results: We outline five overarching themes. Interviews with persons-supported were aided by: 1) negotiation with research ethics officers to allow recruitment and consenting by an intermediary (i.e. PHSS); 2) using copies of the PCP in the interview as a common point of reference; 3) the presence of staff who facilitated communication; 4) organizational support in recruiting participants and scheduling interviews; and 5) having a trained interviewer with experience working with persons-supported and knowledge of adapted processes for individual capacity and circumstances.

Discussion: Conducting interviews with persons-supported is consistent with a “nothing about us without us” approach, but requires attention to ensure ethics requirements are satisfied and individual and practical considerations are incorporated into the research plan. An integrated knowledge translation approach, wherein researchers and providers work closely together to develop the research plan, is integral to facilitating participation of persons-supported in research.

Conclusion: Creative and flexible approaches are needed to include persons-supported in research.