

## CONFERENCE ABSTRACT

# What Factors Influence Patient and Carer Engagement in Community Based Primary Health Care? Insights from People with Complex Care Needs and their Carers

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**Introduction:** Patient engagement, defined loosely as “involving patients in their care” is a popular buzzword used across health systems internationally. Moving from paternalistic “providers know best” delivery models to those that foster collaborative partnerships between patients, families and providers is being increasingly emphasized within health systems. In order to best engage patients and families in their care it is critical to understand the factors that help or hinder such engagement. Community based primary health care (CBPHC), defined as the integration of primary care with community services is touted as an ideal place for such engagement activities to occur and is the context for this research.

**Theory/Methods:** This study is part of a programme of research called Implementing integrated Care for Older Adults with Complex Health needs (iCOACH). Semi-structured interviews were conducted with 112 participants: patients with complex needs (primarily older adults) and with informal carers across Canada (Ontario, Quebec) and New Zealand who were clients of selected CBPHC models. Interviews captured the characteristics and needs of patients and carers, and were audio-recorded and transcribed verbatim. Interviews were reviewed by multiple team members and a consensus codebook was created. Codes which captured unmet need, patient and provider communication and trust were extracted and analyzed inductively to identify patterns and factors which seemed to influence engagement.

**Results:** Four primary barriers to engagement were identified: Perception of services; comfort in asking for things; beliefs about role; and access to resources. Patients and carers were reluctant to use what was available or offered to them due to perceptions of poor quality, which was shaped by previous experiences or observations of the care of others. Patients and carers were reluctant to ask for things due to perceptions that their needs could not be met

or for fear of being reprimanded for voicing unmet need. Role beliefs such as perception of whether or not it was appropriate to question care providers or relinquish personal responsibilities (such as caregiving duties) played a role. Finally, factors such as a common language, adequate health literacy and access to financial resources influenced the extent to which patients and carers could engage with providers.

**Discussion:** In this paper engagement encapsulated both the use and uptake of service as well as involvement in care interactions with providers. How patients and families perceive care, comfort in voicing their concerns, role beliefs and access and personal resources were identified as determinants to participation in health care.

**Conclusions:** (comprising key findings) Creating an enabling environment for patient and carer engagement requires addressing their concerns about the quality of services; providing a safe space for patients and carers to voice their needs and concerns and have collaborative discussions with care providers; addressing feelings of guilt that may emerge among carers who don't want to relinquish their roles and ensuring that patients and carers are provided with resources to enhance health literacy and access to care.

**Lessons learned:** In order for patient and carer engagement to be an equitable practice addressing these barriers is required.

**Limitations:** Insights from patients with cognitive impairment are not included in this study.

**Suggestions for future research:** Future research can utilize co-design methodology to develop and test interventions with patients and carers that address these barriers in an effort to enhance participation in health care.

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**Keywords:** patient and carer engagement; equity; community based primary health care; access to care

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