
CONFERENCE ABSTRACT

Working Together-Planning together. A participatory experience-based co-design approach to build an integrated palliative care model in Ontario, Canada.

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Introduction: With the increase in life expectancy and the development of medical knowledge, the expectation that individuals will live a quality life till the very last days is becoming the norm. Palliative care is an approach that improves the quality of life of patients and their families facing the issues associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, comprehensive assessment and a management plan that considers, physical, psychosocial and spiritual needs. Despite this wholesome definition, the majority of palliative care interventions remain localized and siloed.

Context: In 2019, the Ministry of Health in Ontario, Canada, announced the Ontario Health Teams (OHTs) as an innovative integrated care network model to deliver integrated person-centred care to Ontarians across their life trajectory (currently there are 54 teams covering 95% of the population). These teams utilize a population health management philosophy to integrate care in a person-centered manner. Integrating palliative care across care sectors and along the trajectory of the palliative care journey is a priority to many of these teams.

Approach: In the Spring of 2022, Burlington OHT formed a working group to co-design an integrated palliative care model. This working group included patients, caregivers, palliative care physicians and nurses, primary care physicians and nurses, home and community care providers, hospice care providers, policy makers, researchers and evaluators. A participatory experience-based co-design approach was taken to identify the gaps, determine best practices, design a new care model, create an implementation plan, implement, evaluate and improve.

The participatory experience-based co-design approach was guided by the 11-step methodology described by O'Cathain A, et al in 2019 when co-designing complex health interventions. We added some additional steps. The modified methodology included 1) planning the co-design process, 2) involving all stakeholders (including those who will implement, deliver, use and benefit from the intervention), 3) bring together a team and establish decision-making processes, 4) needs assessment via multiple engagement tools (surveys and virtual and in-person engagement sessions), 5) review published research evidence, 6) draw on existing theories/frameworks, 7) identify relevant change ideas, 8) articulate programme theory, 9) undertake primary data collection, 10) understand the local context, 11) pay attention to future implementation of the

intervention in the real world, 12) design and refine the intervention and finally 13) implement and evaluate.

The project is in its concluding stages and the final findings including the detailed integrated palliative care model description and the implementation plan will be available for the conference in May

Implications for applicability/transferability: Designing integrated palliative care programs is a novice area of integrated care across the world. Describing the participatory experience-based co-design approach that we followed to plan our intervention has a great potential of guiding policymakers, planners, funders and implementers on how to plan and implement such interventions by facilitating a work together-plan together approach.