CONFERENCE ABSTRACT

Integrating community-based nonprofit organizations into the cancer care journey: how do connections and coordination take shape?

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Background: A cancer diagnosis affects all aspects of a person’s life over long periods of time, creating a range of needs at different times and in different combinations during active treatment, self-management and survivorship. The chronic and multifaceted aspects of cancer have led to an increased recognition that, along with specialized cancer teams, community supports play an important complementary role in ensuring the well-being of people living with and beyond cancer. In many jurisdictions, community-based nonprofit organizations provide services that help people cope with the impact of cancer on their lives, navigate the complex cancer system, and manage their distress. Currently, these organizations are poorly integrated into cancer networks, so many cancer team members and patients are unaware of the services offered, resulting in their underutilization.

This issue remains underexamined in the literature, which nevertheless identifies the potential benefits of community supports on well-being and on reducing unmet needs of individuals. In Quebec (Canada), the Ministry’s Cancer Plan recognizes community-based nonprofit organizations as essential complements to medical, nursing and psychosocial care. However, at the local level, there is little guidance on how to ensure that people are informed about and referred to appropriate community services and that their needs are met.

Purpose: Our communication presents the results of a study that sought to explain how connections and coordination are taking shape to innovate in the integration between community-based nonprofit organizations and cancer care providers.

Methods: We undertook a qualitative study actively involving patients to address these issues. The objective was to discover how new connections are taking shape between people living with cancer, cancer teams, and nonprofit organizations. Participants came from two regional cancer networks with different patient's pathways. Interviews with cancer team members (n=9), community-based nonprofit organizations members (n=16), and people living with cancer (n=21) sought to explain how linkages and coordination between cancer teams and nonprofit organizations were provided for people who might benefit from community organizations. An analysis based on the theoretical framework of proximity dimensions (geographic, cognitive, relational, organizational, institutional) was undertaken to understand how new practices emerged between the clinical and community spheres, as well as the factors that enabled or hindered coordination along the cancer journey.
Results: We found that referrals to community-based nonprofit organizations were supported by cognitive proximity, where actors had a similar understanding of the needs of people living with cancer and the contribution of community organizations; and geographic proximity, where community organizations were present within the cancer clinic. Cognitive and geographic proximity contributed to relational proximity between cancer teams and community actors. We also found that people living with cancer often self-referred to community organizations and played an important role in establishing links between the clinic and the community sphere. However, some were reluctant because they felt that others were more in need of these services. Considerable variability in knowledge and referrals, as well as this patient hesitancy, suggests a lack of institutional proximity, or systemic support, for coordinating community services as an integral component of integrated cancer networks.