

Parachute: An action-research study on transition to promote wellbeing and flourishing

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Background

When young individuals with chronic illnesses transition into adulthood, they must integrate the adult healthcare system to ensure the stability of their health. Youths in this situation they may face significant challenges that are associated with suboptimal transition practices such as cessation of medication, important delays for adult care admission, and discontinuation of healthcare [1]. The importance of improving transition care services is emphasized by numerous guidelines and consensus statements produced by Canadian and international pediatric healthcare organizations. While significant attention is given to the transition, most programs implemented in hospitals focus on the “transfer of care”, namely, the transfer of medical records from one system to another [2, 3, 4] and transition programs are generally oriented towards maximizing medical compliance and treatment adherence, thereby placing high value in concepts such as autonomy and independence [5, 6, 7, 8]. Autonomy-centered transition programs may not reflect the values of all youths and their families, whose values may differ from those of the healthcare system and ensuring that transition programs are conceived *for* and *by* youths and their families through participatory research could help minimize this pitfall [9]. Considering this, including youth wellbeing and flourishing during the transition period is important [4].

Affiliations



Funding



METHODS

Phase 1

Identify and validate the stakes of transition

Interviews

54 interviews with young adults, parents and healthcare professionals

Survey

Validation of the themes, stakes and recommendations identified in the interviews

Phase 2

Elaborate methods of intervention

Codevelopment of video clips with youth with chronic illnesses

Phase 3

Evaluate the interventions

Interventions

Series of sensitization workshops on the stakes of transition with healthcare professionals

Themes that emerged from the interviews [9]

1. Continuity in care
2. Multidisciplinary care
3. Adapting to a new care
4. Knowledge and information about the transition
5. Knowledge and information about the medical condition
6. Patient involvement in healthcare decisions
7. Health management
8. Variability in autonomy
9. Parental involvement in healthcare
10. Confidentiality
11. Relational continuity with healthcare professionals
12. Social connection
13. Navigating life with chronic illness
14. Development into adulthood



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