
CONFERENCE ABSTRACT

Care transitions across the lifespan for Canadians with sex variations

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Introduction

Sex variations comprise a heterogeneous group of medical conditions. These include congenital adrenal hyperplasia (CAH), androgen insensitivity syndrome, Turner syndrome, and more, reportedly affecting approximately two percent of the population. These conditions can involve lifelong management. However, no research has examined the experiences nor the healthcare practices used with these individuals in their transitions through healthcare in Canada. Further, the majority of research on healthcare transitions from other countries focuses on the pediatric to adult care transfer, despite transitions taking place across the lifespan.

Aims Objectives Theory or Methods

Firstly, we aimed to investigate the current context of care for individuals with sex variations through an environmental scan of the current care pathways and guidelines for transition used by health providers. This included a search of 13 Canadian Children's Hospital websites, a survey sent to providers, and freedom of information requests submitted to these hospitals. Secondly, we sought to learn from the experiences of individuals with sex variations and their families in transitioning through care, along with their providers' understandings of transition for this group. Thus, we conducted engagement sessions in BC and Ontario applying a community-participatory learning approach

Highlights or Results or Key Findings

Through the environmental scan, we found no hospital-specific resources used by healthcare providers for guiding care transitions for individuals with sex variations. Our engagement sessions consisted of in-person focus groups and virtual interviews with individuals from Ontario and British Columbia. We also included secondary data from a small BC study with women with CAH.

Altogether, data from 17 individuals (15 with sex variations and two caregivers) was included. Interviews highlighted three important themes: (1) transition is a lifespan activity – individuals faced different healthcare challenges that required transition as they aged, (2) the building of personal agency, and (3) wellness promotion and healing in this population. An additional output from the study included the co-development of a small advisory group of adults identifying with sex variations, involved in work around health education and consultation.

Conclusions

Canadian care guidelines for managing transition with sex variations are lacking. For individuals with sex variations there is little information to support individual health literacy and selfmanagement. There exists an opportunity for these individuals and their providers to begin building a visible network that can inform care delivery and policy.

Implications for applicability/transferability sustainability and limitations

A limitation of this study was failure to adopt inclusive terminology at study conception (e.g., our website domain, dsdtransition.ca). We learnt that intersex or sex variation is preferred by the community. We encourage use of inclusive terminology in healthcare and the co-development of transition guidelines with Canadians with sex variations