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Review article

Using the ICF in transition research and practice? Lessons from a scoping review

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ABSTRACT

Background: The International Classification of Functioning, Disability and Health (ICF) and subsequent ICF-CY (child and youth version) recognize the importance of personal and environmental factors in facilitating holistic transition planning and service delivery for youth with chronic health conditions (YCHC).
Aims: The objective of this scoping review is to investigate the degree to which the ICF and ICF-CY have been used in transition research and practice since its initial publication.
Methods: Arksey and O'Malley's five-stage methodological framework guided the scoping review using the following databases: AMED, CINAHL, EMBASE, HealthSTAR, MEDLINE, and PsycINFO. Keywords included: 'ICF', 'ICF-CY', and 'transition', which were adapted to each database.
Results: 25 articles met final inclusion. Two key themes emerged regarding use of the ICF: 1) the ICF enhances transdisciplinary processes to inform transition planning and interventions; and 2) the ICF facilitates comprehensive and developmentally appropriate transition services over a youth's lifecourse. The strengths and limitations of the ICF in guiding the planning and delivery of transition services are discussed. Some limitations include the large number of items inherent within the ICF and a lack of clarity between the components of activity and participation.
Conclusion: Key recommendations include: i) further explanation and development of items for quality of life and well-being, personal factors, and psychological issues; and ii) additional research to advance knowledge towards developing empirically- based evidence for the application of the ICF in clinical practice to facilitate transition.

What this paper adds

The findings of this scoping review advances knowledge about how the ICF framework can be implemented in the planning and delivery of transition services to address some of the current knowledge gaps, including: i) provision of a common language and an internationally recognized transdisciplinary framework to guide interventions, goal-setting, evaluation procedures, assessing and monitoring progress and healthcare outcomes; ii) shift the focus from diagnosis and treatment of somatic issues (illness, injury, or

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other health condition) to functional abilities (activities and participation); and iii) address the developmental needs of transitioning youth over the lifecourse. Limitations of the ICF in transition services include: i) a lack of clarity between the components of activity and participation, ii) the need for the development of a new ICF scheme to be more reflective of a biopsychosocial perspective, and iii) the large number of items can make the ICF cumbersome to use thus, development of a core set is needed for transitioning YCHC.

1. Introduction

Becoming an adult is a complex and multifaceted process for all youth. The challenges associated with the transition to adulthood are magnified for youth with chronic health conditions (YCHC) as transition involves multiple concurrent changes in the domains of housing and accommodations, finance, education, relationships, employment, leisure and transportation (Donkervoort, Wiegerink, Van Meeteren, Stam & Roebroeck, 2009; Goudie & Carle, 2011; Vogtle, 2013; Foley et al., 2013). During this volatile period YCHC struggle with continuity of care and access to necessary services. (Hsieh et al., 2017; Bindels-de Heus et al., 2013; McGorry, Bates, & Birchwood, 2013; Singh, 2009). YCHC and parents have expressed a need for continuous and coordinated services as well as clarity and assistance with navigating the transition process (Major et al., 2014; Sonneveld, Strating, van Staa, & Nieboer, 2013). Although the topic of transition is not a new phenomenon, as the research and literature is well established, the authors wanted to explore the common features of this process through the lens of the International Classification of Functioning, Disability and Health (ICF) to gain new insight into the transition process (World Health Organization, 2001). It is important to re-examine transition through a fresh lens to better understand the issues. In the context of this review, YCHC refer to people often described with terms like ‘adolescent’, ‘young adult’, ‘teen’, ‘transition-aged youth’, and ‘emerging adult’ ages 12–25 with a wide range of chronic health conditions and youth with developmental disabilities. To strengthen the applicability of the results, the authors took a non-categorical approach by casting a wide net to focus on YCHC rather than focus on a specific condition. The age range of YCHC was also selected to reflect the common age range of transition-aged youth as reported in the literature (Gorter et al., 2014).

It may be helpful to start by re-examining the goals of healthcare transition: “to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate healthcare services that continue uninterrupted as the individual moves from adolescence to adulthood. It is patient centred, and its cornerstones are flexibility, responsiveness, continuity, comprehensiveness, and coordination” (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine, 2002). There are a few significant knowledge gaps in research and practice to extrapolate from this definition. First, current transition services are often not reflective of YCHC’s lifelong needs, as they are deeply rooted in the traditional biomedical model that is diagnosis-driven and static rather than continuous and coordinated (Wang, McGrath, & Watts, 2010). YCHC often have pervasive functional impairments that are lasting, requiring a continuum of services that is coordinated and uninterrupted (Reed, Spaulding, & Bufka, 2009).

Second, there is a lack of developmentally appropriate transition services that address YCHC’s dynamic needs across the lifecourse in adult services to gradually prepare them for adult roles and responsibilities (Scal, 2016). Furthermore, there is a lack of collaboration and integrated services among professionals involved in transition as various service sectors are still working in silos. Scal (2016) stated “Pediatrics’ strong tradition of attending to children’s developmental needs can and should be leveraged to extend the same quality of care to our adolescent patients” (Scal, 2016, p. 198). Results of a systematic review on philosophies of care by Mulvale et al. (2015) found that generally (acknowledging exceptions), pediatric services also tend to be more youth-centred and family-centred compared to adult services (Mulvale et al., 2015). Third, YCHC have a wide range of needs beyond healthcare during transition to adulthood, including financial, emotional, sexual, behavourial, and social issues that are often not fully addressed in current practice and require additional attention (Reiss, 2012). For example, Fair et al. (2016) found that areas in need of additional consideration and research in transition include outcomes such as quality of life, self-management, understanding health insurance, and having a social network. Additionally, a recent systematic review by Young-Southward, Philo, and Cooper (2016) revealed a gap in the literature regarding transition and health including issues with sexual health. Lastly, there are no standardized frameworks or practice guidelines that have been implemented consistently to inform the delivery of transition services across various service sectors (English and Pajevic, 2016). Given these significant issues, a consistent framework to guide the planning and delivery of transition services, as well as informing research, would be helpful in bridging these gaps.

Recent literature has explored a trend towards an ecological approach to address the identified service gaps due to lack of permeability between silos and services in transition (Franco, Bouma, & van Bronswijk, 2014; Wang, McGrath, & Watts, 2010). Researchers and clinicians have promoted utilization and implementation of the ICF framework in transition research and practice, as it has the potential to propel a paradigm shift on health and disability (World Health Organization, 2004) (see Fig. 1). For example, Nguyen and Gorter (2014) explored the potential use of the ICF domains and framework as tools to guide the planning of three phases of the transition journey: the preparation, the journey itself, and the landings in the adult world. The ICF provides a conceptual framework and classification system that promote a comprehensive approach to transition services through a biopsychosocial perspective on health to include personal and environmental factors as well as shifting the focus to functional abilities (World Health