Youth in transition: care, health and development

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Youth and transition

In their journey toward adulthood children experience multiple transitions (Kirk 2008). Some transitions are determined by age or development, while others are dictated by ‘systems’, for example, the educational system or healthcare system. Traditional markers or key transition points include entering and leaving high school, leaving the parents’ home and forming ‘a couple’, and getting a job. In the 21st century, youth development and transition into adulthood have become less straightforward and trajectories can go in many different directions.

The term ‘youth’ has not been clearly defined in the literature (Gaudet 2007). There is no agreed-upon age boundary, although recent reports have suggested using the age range of 15 to 24 (United Way of Calgary and Area 2010). Adolescence is defined by the World Health Organization as the period of life between 10 and 19 years of age (WHO 2010). Recently the term ‘emerging adulthood’ (Arnett 2004) has been suggested to describe a new stage in the life course of an individual, one that is typically marked by high school graduation. Many young people in their late teens and early twenties feel they are neither teenagers nor adults. In this editorial, the term ‘youth’ will be used to represent the full developmental continuum of adolescence into young ‘emerging’ adulthood, from ages 10 to 25.

With advances in medical technology and healthcare, survival rates have increased and most children with chronic health conditions or disabilities become adults (Blum et al. 1993). Although there is insufficient evidence from longitudinal studies to compare developmental trajectories and transitions between youth with and without chronic health conditions, a recent knowledge synthesis showed that there are currently more negative than positive adult outcomes for youth with disabilities (Gorter et al. 2011). The reality is that youth with chronic health conditions are involved in many more ‘systems’ than their healthy peers and these systems have age requirements for discharge and transfer. For example, health care and social services are organized into paediatric systems that usually

In the past lies the present, in the now, what will be.
– Willem Bilderdijk (Citation translated from Dutch ‘In het verleden ligt het heden, in het nu wat worden zal’)

Willem Bilderdijk (1756–1831), Dutch writer and poet, son of an Amsterdam physician. When he was 6 years old he was struck by an accident to a foot, causing inflammation of the periosteum. Medical errors caused him to stay inside, shut off from the outside world and his peers. He devoted his childhood and youth to study, drawing and writing. He became a historian, linguist, poet and lawyer. Source: http://en.wikipedia.org/wiki/Willem_Bilderdijk
end at the age of 18 and adult service systems. These two systems are very different in terms of their expectations of youth and families, and this type of transition can be highly stressful and requires a great deal of planning and preparation (Young et al. 2009).

Youth in transition: a special issue!

This special issue of Child: Care, Health and Development is devoted to articles on youth in transition to adulthood. Although the notion of transition of youth with chronic health conditions or developmental disabilities is not new (Blum et al. 1993), the complexity of transitions and the negative outcomes in health care are now being recognized. In a recent report from the American Academy of Paediatrics (AAP) it was concluded that after nearly a decade of effort, widespread implementation of health transition supports as a basic standard of care has not been realized (AAP et al. 2011). Without doubt transition to adulthood is an important ‘21st century’ child and youth health issue that needs to be addressed. It is hoped that the messages in this special issue will find their way to both paediatric and adult health care providers, policy makers and other people working with youth with a chronic condition or disability.

Transition of youth with chronic health conditions is primarily associated with a transfer in the healthcare system, a one-time event in which youth are merely handed over from children’s services to adult services. The articles in this special issue reflect this to some extent; for example, Van Staa and colleagues (2011) focus on experiences with the transfer to adult care of young adults with various chronic health conditions. Other articles, however, look at transition as a gradual process, one that should be age and developmentally appropriate, addressing the psychosocial and educational/vocational aspects of care in addition to the traditional medical areas. Studies on transition are traditionally executed within one specific chronic health condition or within a group of conditions/disabilities, for example, developmental disabilities. Our articles include a focus on autism spectrum disorder (McConachie et al. 2011), cystic fibrosis and congenital heart disease (Moola & Norman 2011), diabetes mellitus (Price et al. 2011), spina bifida (Mahmood et al. 2011; Ridosh et al. 2011) and ‘looked after’ young people (Everson-Hock et al. 2011).

A growing body of knowledge is now revealing that ‘condition’ or ‘impairment’ is only one factor in the developmental trajectory of youth, and that supports and barriers to transition are similar across different types of conditions/disabilities. As such, it is also important to study transition of all youth across different systems of care, which, in addition to health, includes education and social care. This special issue includes papers on the healthcare system (Hamdani et al. 2011; Watson et al. 2011) or multiple systems of care (Kraus de Camargo 2011). Researchers and service providers are moving beyond studying the challenges of transition for youth with chronic health conditions or disabilities and are beginning to study ways to support youth, such as parental support (Kingsnorth et al. 2011), readiness for transition (Schwartz et al. 2011), new models of transitional care (Watson et al. 2011), improving cooperation between paediatric and adult healthcare professionals (Berg-Kelly 2011), and evaluation of transition programmes for youth (Grant & Pan 2011). The current knowledge and perspectives of youth, parents, service providers, policy-makers and researchers laid down in the articles in this special issue reflect traditional views about development, youth and transition over the last few decades; in other words, ‘in the past lies the present’. At the same time many authors bring new ideas for research and practice to move the field forward. Change may not come easy in the field, but there is the promise that today’s thinking on the themes ‘care, health and development’ will be translated into ‘what will be’.

Care

Although moving on to adult care is seen by most youth, parents and service providers as a welcome and positive challenge (Van Staa et al. 2011), virtually all papers on youth with chronic conditions or disabilities indicate that the reality is that transition remains problematic. Indeed, the transition process within the healthcare system alone is more complex than a simple transfer of care from paediatric to an adult setting (Kraus de Camargo 2011).

At the person level

The first question we should ask ourselves about transitional care for youth with chronic conditions is ‘who do we care for’? In our traditional biomedical approach the focus, appropriately, is on stopping, limiting or at least controlling the disease, for example, ensuring acceptable blood glucose levels in diabetes mellitus (Price et al. 2011), or ‘fixing’ the impairments in persons’ body function and structure, for example, reducing the incidence of bladder infections in spina bifida (Mahmood et al. 2011). Individualized person-centred care, strengthening independence and encouraging self-management from childhood, throughout adolescence and into adulthood, are all evidence-based strategies (Mahmood et al. 2011; Fletcher-Johnston et al. 2011; Van Staa et al. 2011), which are still not...
effectively implemented in clinical practice. Possible solutions may be, for example, the implementation of health educational initiatives for individuals or for groups to improve self-management (Mahmood et al. 2011).

It may be that we overlook an essential element in working with adolescents, as Kraus de Camargo points out in this volume: ‘As professionals, we are a significant part of our patient’s context and should function rather as facilitator than as barrier’ (Kraus de Camargo 2011). To achieve this, it is recommended that one person is identified, who acts as a continuous contact who not only cares for the medical problems related to the disease, body functions and structures but also includes a focus on daily functioning, including meaningful participation (Kingsnorth et al. 2011; Kraus de Camargo 2011). Valuing the personal characteristics of youth and identifying their needs, wishes and aspirations are important ways to provide effective adolescent health care (Kraus de Camargo 2011; McConachie et al. 2011; Price et al. 2011). This is supported by the work by Price and colleagues (2011) who argue for staff training programmes in adolescent health, including engendering improved communication skills among professionals by experiential learning methods such as observation, role play and discussion of case studies. They also suggest involving youth in the design of such programmes, given the evidence that young people wish to be involved in service design and delivery (Kingsnorth et al. 2011; Price et al. 2011). Importantly, transitional care is as much about us (professionals) as about them (youth)!

At the programme level

Despite position papers with recommendations for improving transition in health care by notable professional organizations such as AAP, the Canadian Paediatric Society, the Society for Adolescent Medicine and best practice guidelines for the transition to adulthood for youth with disabilities (http://www.canchild.ca), there remain many barriers to developing transitional programs and to implementing them in practice (Stewart 2009; AAP et al. 2011; Grant & Pan 2011). The principles of transition that should form the basis of any transition program are common to all chronic conditions and disabilities. A wide range of models has been developed, some in isolation and others built on previous programs.

In this special issue Grant and Pan (2011) summarize five programs for youth with chronic illness in paediatric academic settings across Canada. These programs show many underlying similarities and themes, but only two of the five programs address all principles. For youth with chronic illnesses (Grant & Pan 2011) and for young people with Autism Spectrum Disorder (ASD) (Watson et al. 2011) it was found that services lack formal evaluation and sustainability. It is alarming to see the lack of evidence of effectiveness of programs and models of care. Instead of ‘reinventing the wheel’ service providers in paediatric and adult settings should both build on existing programs and incorporate modern thinking on transition. For example, in this special issue many authors indicate the importance of adopting a bio-psycho-social model of health rather than a biomedical model (Kingsnorth et al. 2011; Kraus de Camargo 2011; Moola & Norman 2011; Price et al. 2011; Schwartz et al. 2011). Theoretical and practical models can guide and develop new transitional programs, for example, a system model (Hamdani et al. 2011), the International Classification of Functioning, Disability and Health (WHO 2001; Kraus de Camargo 2011), and the chronic care model (Mahmood et al. 2011). Crucially, transition programs should be made available and accessible to all youth who need them, including disadvantaged or minority groups (Everson-Hock et al. 2011), youth with significant cognitive impairments, youth with mental health and behavioural problems (McConachie et al. 2011) and youth with multiple disabilities or conditions (Gorter et al. 2011), usually requiring diverse services and supports.

It is not just the adolescent on whom transition programs should be focussing. As adolescents are nested within a family system, parents and other family members need resources and information to support their adolescent into emerging adulthood. Not surprisingly, it is recommended that parents be involved in the transition process (Kingsnorth et al. 2011; McConachie et al. 2011; Van Staa et al. 2011), especially when the young person is reliant on their support (McConachie et al. 2011). Parents require ongoing and co-ordinated support to navigate the complex process of service transition (Kingsnorth et al. 2011). Transition co-ordinators or key-workers could assist families and youth finding resources and information to make informed decisions. The facilitating role of parents can be strengthened through parent to parent support, for example, through sharing experiential knowledge (Kingsnorth et al. 2011). Similarly, new transition supports should also consider the potential of the lived experience of young adults as youth facilitators (Kingsnorth et al. 2011). Just as adolescents are nested within a family system, families are situated within communities. Therefore, advocacy is needed to ensure that adequate resources and supports are available to youth with chronic conditions and their families to support inclusion at the community level. This includes a range of options for funding, housing, education and employment.
At the policy/legislation level

Transition of youth takes place in multiple systems such as health, education, social, child protection and justice systems. There are inconsistencies across different systems, which make it extremely difficult to work collaboratively towards a life course approach (Gorter et al. 2011; Hamdani et al. 2011; Kraus de Camargo 2011). Consistency and collaboration are needed across all systems, such as defining and agreeing on the age range of youth and related services, addressing the needs of youth requiring diverse service and supports, and developing meaningful outcomes. Collaboration is also needed to provide person-centered planning at important transition points. Kraus de Camargo found that most literature on legislation and policies with regard to systems and transition stems from North America (USA and Canada) and Europe (Germany and UK), with only articles from the UK illustrates attempts to create a fully integrated system (Kraus de Camargo 2011). In the Netherlands, for example, there are no national policy documents advocating transitional care, and few professional guidelines addressing this issue (Van Staa et al. 2011). However, having a UK Autism Act that requires that services for adults with ASD be developed is not a guarantee that the transition support and services are available to the people who need them (McConachie et al. 2011).

What then can be done to ensure that youth are not only ‘free of problems’ but that policies and systems help youth prepare to thrive? First, there is a need to develop policies to move current evidence on positive youth development (Hawkins et al. 2011) and best practices (Stewart et al. 2009) into use. For example, implementation of collaborative written transition plans for education, health care and social systems can provide youth and families with useful and relevant information to help them make informed decisions for the future. Ideally, there should be one integrated, actualized, mobile and accessible transition plan for every young person. Second, policies are needed to promote the evaluation of services and models as well as funding of holistic, longitudinal studies providing evidence on the long-term outcomes. Ideally, outcomes would focus on participation, citizenship, community engagement and other ‘rights’ that are meaningful to all youth with chronic conditions or disabilities and their families. Third, policies are recommended to ensure that adequate resources and supports are available to all youth and their families to maximize participation and inclusion at the community level. (Shikako-Thomas et al. 2008).

As the issues related to the transition to adulthood for youth with chronic conditions and disabilities are a worldwide health problem, why then do we not aim for a ‘youth in transition’ decade worldwide to be endorsed by WHO and health professional organizations around the world? The goal of such a global campaign should be to improve the quality of life for all youth by ensuring appropriate health care and creating opportunities for youth transitioning into independent living settings and the workforce. Of course, we cannot leave it to policymakers or the United Nations. It is a shared responsibility of families, service providers, communities and governments to reduce barriers within and between systems, and most importantly, to reduce the divide between the paediatric and adult world.

Health

Difficulties in effective transition of youth in healthcare are associated with poor health outcomes and a loss to follow-up (Crowley et al. 2011). Although rigorous data from longitudinal studies on health in youth with chronic conditions or disabilities are scarce, there is a growing body of knowledge that young people with chronic health conditions or disability are at risk of developing other serious health problems. For example, youth with ASD are at increased risk of developing mental health problems (McConachie et al. 2011), and physical disability, such as cerebral palsy, is associated with an inactive lifestyle, which is associated with obesity, increased cardiovascular disease and cancer (Gorter 2009). Research is needed not only to identify risk factors for secondary – and thus to a large extent preventable – health problems (Mahmood et al. 2011). It also is hoped that research programs will be developed to identify, understand and ultimately reduce the risk of comorbidity in youth with chronic conditions by focussing on novel strategies to promote physical activity, an active lifestyle and autonomy. Promising studies are currently developed and underway, for example, the Stay-FIT study that aims to investigate innovative approaches broadly applicable to youth with cerebral palsy, to promote an active lifestyle and community participation (Claassen et al. 2011).

Without doubt transition from paediatric to adult health care is an important issue for both the research and clinical communities. Interestingly, the perspective of youth with chronic conditions or disability health is only one of many aspects of their lives. In a recent qualitative evaluation in an ongoing study about youth with various conditions in their transition from the paediatric to adult health care settings it was found that an Internet-based transition co-ordinator and Youth Kit® (a tool that promotes information-gathering and self-management) were most helpful to participants for transitions related to jobs,
school and relationships (Punthakee & Gorter 2011). Health and health care were not mentioned by youth themselves in the Transition to Adulthood with Cyberguide Evaluation (TRACE) study (Punthakee & Gorter 2011). This may be due in part to the youths’ narrow view of health. The literature on the unique needs and experiences of youth has taught us that health should be broadly defined and include physical, social, cognitive and emotional aspects with ‘participation’ as the ultimate measure of outcome (i.e. involvement in a life situation) (WHO 2001). It is important to understand a young person’s functioning by examining the interaction between health condition, environmental factors and personal characteristics and preferences (Kraus de Camargo 2011). Functional profiles, based on the International Classification of Functioning, Disability and Health, rather than the medical diagnosis alone, can be useful in designing better interventions by addressing activities that youth consider important in their daily living.

Development

The idea that youth development is a linear process from childhood via adolescence to adult life is ‘past thinking’, although information in current textbooks and youth policies is still organized along the lines of the traditional ‘ages and stages’ structure. Although there are patterns of physical, cognitive, social and emotional changes that youth undergo, beginning with puberty, these changes often occur simultaneously or in rapid succession. In reality, youth development is much more complex than biological growth and maturation. In this special issue new perspectives are offered that make us realize that a number of paradigm shifts are underway in clinical practice and research with respect to youth development in general and transition to adulthood in particular. Current theories focus on understanding development of youth in close relation to their context and living environment (home, school and community). Research on factors that influence developmental trajectories has shifted from an approach of considering personal and environmental factors separately, to an interactive view of person–environment factors that influence and mediate each other. Informed by theoretical insights from new social studies, Moola and colleagues (2011) conceptualize childhood and youth as culturally constructed categories. Much can be learned about youth development and transition by giving youth a voice. Because of the constraints and uncertainties that come with chronic conditions, concepts such as the future and time are relevant to young people’s transition experiences. Moola and colleagues suggest expanding the definition of transition to include social and relational aspects of young people’s lives. While transitional concerns appear to intensify at the age of 17 prior to the transfer of care, in their study Moola and colleagues (2011) showed that children as young as 12 appear to contemplate transition. There is convincing evidence that the process of transition should start early with a life course approach to development and transition, recognizing the chronic nature of childhood illness and disability (Priestly 2001). Theoretical models can help guide research and clinical practice, for example, to develop measures to assess transition readiness to adult care (Schwartz et al. 2011). A pilot study in cancer survivors showed that factors in the person (e.g. age, disease skills and knowledge) as well as environmental factors (e.g. variables related to the health care provider and variables related to positive youth outcomes such as leaving their family home and establishing independence) are associated with transition readiness (Schwartz et al. 2011).

In conclusion, developmental trajectories of youth can go in many directions, depending on the interaction of personal risk and protective factors with environmental barriers and supports. These interactions are most important at transition points, when a young person is dealing with significant changes in personal and environmental changes. It is through positive, developmentally appropriate life experiences throughout their childhood and adolescence and regular opportunities for participation and inclusion that youth can prepare for a successful and meaningful adult life.

Conclusion

The articles in this special issue add to our knowledge of care, health and development for youth with chronic health conditions, leading to greater understanding of the facilitators to promote transition planning and improve clinical practice. The promise that the new paradigms on youth development and transition will improve the lives of all children is greater than ever. Therefore, we need evidence showing ways to bridge the divide between child systems and adult services to inform policies and legislation. This can be done through advances in medical and psychosocial care guided by sociological and developmental theories and models, and through research focusing on life course, person–environment interactions and processes at work to provide youth with chronic conditions with experiences and opportunities needed for positive development. Above all, good clinical practice needs to be coupled with effective self-advocacy as well as advocacy. It is hoped that
our increasing knowledge will benefit all children and youth with health-related problems of today who are the adults of tomorrow.

References


