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The evidence highlights a shift in the epidemiology of children and young people's health from acute illness to long-term or chronic conditions (World Health Organisation, 2002). The actual number with a chronic condition is unknown (Jackson Allen, 2009) but we do know that there is an upward trend in the prevalence of long-term conditions that are severe enough to limit activity and delay normal developmental milestones, whilst reducing the quality of life of affected children and young people, their parents, carers and siblings. Moreover, we now know that what happens in early life affects health and well-being later in life (Chief Medical Officer, 2012); while better screening for and earlier detection of chronic conditions, coupled with improvements in the delivery of specialised care has meant improved survival for those with chronic conditions (Halfon & Newacheck, 2010). However, improved survival is not without a cost for families and society. Living with one or more conditions affects individuals in several ways. Children, young people and families may need multiple contacts with health-care professionals at home and in health-care settings, across the life span; they may need to manage complex treatment regimens, whilst also coping with financial difficulties, emotional and psychological problems, and even social isolation from peers.

As health-care professionals, our aim is to promote the best possible experience for such families while contributing to optimum clinical outcomes for children and young people. The fifteen articles in this special issue explore and discuss a wide range of challenges that face those living and working with the consequences of chronic conditions. In keeping with the journal's aim to publish research papers on a variety of topics, in this Issue the authors used a range of research methods to address their topics of interest. Seven studies used qualitative methods, two used mixed-methods, one used a quantitative approach and one reported on a case-study of medical records. Two articles report on literature reviews and one on a concept analysis. As befits a Special Issue in a journal that is increasingly international in its reach, the articles published here represent authors from seven countries (China, England, Germany, Ireland, North America, Sweden and Wales).

The Journal is built on the principles of child-health nursing, and nurses also work within multidisciplinary teams, therefore, it is encouraging to note that whilst the lead author of 12 of the articles is a Nurse, two of these nurses also have a Social Work qualification. In addition one lead author is an Occupational Therapist, one is a Health Psychologist and one is a medical Doctor. Several of the authorship teams are multidisciplinary. The diversity continues when we read about the range of populations that co-participate in healthcare and who are represented here; these include children and young people as patients and as siblings of patients, mothers and fathers of patients, families as the unit of study, and healthcare professionals. Furthermore the range of conditions and health-care contexts discussed in this issue is extensive.

For example, two articles consider the challenge of living with a rare condition: *Dr Carlsson's* article *CHARGE syndrome-a five case study of the syndrome characteristics and health care consumption during the first year in life* observes that these infants and their families need multiple health care contacts and so recommends coordinated and individually adapted care; while *Dr Glenn* undertook a phenomenological study of 16 mothers of children with Alagille syndrome, her article, *Using Online Health Communication to Manage Chronic Sorrow: Mothers of Children with Rare Disease Speak* suggests that these mothers need emotional support and help accessing appropriate online resources.

The views and experiences of patients are explored in several articles. *Drs Beacham and Deatrick* interviewed 8-13 year olds with asthma, diabetes and cystic fibrosis in *Children with Chronic Conditions: Perspectives on Condition Management* and explain that children in this age group view condition management in ways similar to their parents and have developed their own management routines. *Drs Cardell, Clark and Pett* considered *Measurement Considerations for Achieving Equity in Research Inclusion for Transition-aged Youth with Disabilities* and recommend reliable and valid youth-specific measures to promote research inclusion and reduce health disparities. Children with life-limiting conditions and their families were the focus of a qualitative study by *Dr Coad et al*, *Exploring the perceived met and unmet need of life-limited children, young people and families*. Their findings tell us that children and families feel their medical/nursing needs are well met but that a need exists for financial, social and emotional support alongside specialist therapies. Meanwhile, *Lowes, Eddy, Channon, Mcnamara, Robling and Gregory* in an article entitled: *The experience of living with type 1 diabetes and attending clinic from the perception of children, adolescents and carers: analysis of qualitative data from the DEPICTED study* indicate that professionals caring for those with type 1 diabetes and carers, need training in patient-centred communication skills so that patients'/carers' emotional needs can be systematically assessed and addressed. A review of 18 qualitative studies was conducted by authors *Lambert and Keogh*, *Striving to live a normal life: a review of children and young people's experience of feeling different when living with a long term condition* and reminds us of the importance for these children of participation in everyday life-restrictions and adjustments, and how treatment regimens can be both constraining and enabling.

The views of staff are the focus of the article: *Individualising Hospital Care for Children and Young People with Learning Disabilities: It's the little things that make the difference* by a team led by *Dr Oulton*. This ethnographic study emphasises that parents play a central role in staff's delivery of individualised care but that a lack of staff experience, knowledge and communication about learning disability can mean they rely on parent's input rather than forming a true partnership with them. The value of technology in modern health care was the subject of *A Critical review of the use of technology to provide psychosocial support for chronically ill children and young people* by authors *Aldiss, Baggott, Gibson, Mobbs, & Taylor*. The review found that supportive technologies did not improve quality-of-life, reduce health service use or decrease school absences. However, the poor methodological quality of current evidence and lack of involvement of users in product development contributes to the uncertainty that supportive technology is beneficial.

We are reminded of the need to consider siblings' perspectives through two articles (i) *Drs Knecht, Hellmers, and Metzling: The perspective of siblings of children with chronic illness*.

This literature review identified a map of dimensions of experiences, well-elaborated as well as fragmentary and advocates further research on sole siblings' perspective (ii) A mixed-method, qualitative dominant design *Childhood Burn Survivors' and their Siblings' Perceptions of their Body Image* by Dr Lehna indicates that children focus on developing a positive body image satisfaction. In light of the growing emphasis on the life-stage approach to long-term condition management it is interesting to consider the longer term consequences of conditions that appear in childhood through *Healthcare System Supports for Young Adult Patients with Pediatric-Onset Chronic Conditions: A Qualitative Study* by Dr Szalda. This work identified practice supports: formalizing intake processes, interoperable electronic medical records, and leveraging care coordination. Barriers included: definition of the medical team, lack of appropriate medical records, time and administrative burden.

Finally, the family is the unit of study in three papers. Drs Baird, Davies, Hinds, Baggo and Rehm asked: *What Impact Do Hospital and Unit-Based Rules Have Upon Patient and Family Centered Care in the Pediatric Intensive Care Unit* in a grounded theory study. The authors identify the existence of explicit and implicit rules all of which negatively affect the family's ability to receive care that is attentive to their needs. The rules also placed the registered nurse in the challenging position of serving as rule enforcer and facilitator of PFCC. Their recommendation for further work to explore how to adapt the hospital environment to better meet families' needs reminds us of the need to consider the family-friendliness of our familiar health-care environments. The paper led by Dr Smith; *Involving parents in managing their child's long-term condition - a concept synthesis of family-centred care and partnership-in-care* presents a unique practical framework of involvement which may promote parent-professional collaboration for families of children with long-term conditions. Lastly, the article by Dr Zhang and colleagues: *Identifying Factors Related to Family Management During the Coping Process of Families with Childhood Chronic Conditions: A Multi-site Study* recommends more family support for those with low family income and those living in rural areas.

Throughout this issue the terms 'chronic' and 'long-term' are used interchangeably which reminds us of the need to be aware of both terms when searching the international literature. It has been a privilege to be the first international issue editor for JPN and to have the opportunity to read and learn from this fine collection of most interesting articles. I hope the knowledge shared here will inform and inspire readers in their teaching, research and clinical practice.

Dr Veronica Swallow, Guest Editor

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