

## Abstract

Chronic condition self-management is well defined for adult populations as the completion of a range of health-enhancing behaviours that a person with chronic condition/s completes autonomously. As a precursor to autonomous chronic condition self-management, for children and young people, supported self-management involves a shared responsibility for the self-management tasks between children and young people and their caregivers that changes over time. There is clear delineation from family management (i.e. in infancy and early childhood) to supported self-management by the child/young person (i.e. in middle childhood, early adolescence and older adolescence) to ideally autonomous chronic condition self-management (i.e. at the point of transfer to adult healthcare services at approximately 18–20 years of age). However, there is currently little evidence available to guide caregivers, clinicians (of various disciplines) and healthcare policy makers in how to best deliver self-management teaching and support approaches to children and young people.

Across the world, including Australia, more than one in 10 children and young people (0–20 years) live with a chronic medical condition/s. This thesis presents new self-management teaching and support approaches specifically designed to fit with the changing needs of children and young people with a chronic condition as they develop and mature (that reflect changing abilities). More specifically, the research investigated three main areas – (1) the role children and young people have in managing their own chronic conditions at various developmental stages; (2) how children and young people undertake shared responsibility for supported self-management with their caregivers; and (3) the teaching and support approaches that clinicians can use to promote growth in supported self-management skills and healthcare behaviours.

This thesis is predominately exploratory and theoretical, reflecting the limited research on supported self-management for children and young people with chronic conditions done to date. Three focus conditions were used to illustrate supported self-management – i.e. asthma, cystic fibrosis (CF) and type 1 diabetes mellitus (T1DM). Furthermore, so that the research findings can be applied more broadly across paediatric health care settings an interdisciplinary lens was applied.

A pragmatic research philosophy using a mixed-methods approach was chosen and four studies were completed. Specific methods used for the studies included:

- **Two systematic reviews**
  - A systematic review of current guidelines for promoting developmentally appropriate supported self-management in children and young people with asthma, CF and T1DM (Published, [Saxby et al. Chronic Illn., 2020](#)) [8]
  - A systematic review of supported self-management education interventions with children young people with asthma, CF and T1DM (Published [Saxby et al., Patient Educ. Couns., 2019](#)) [7]
- A **concept analysis** for supported self-management for children and young people with chronic conditions (manuscript in preparation for publication 2020)
- A **Delphi consensus** of developmentally appropriate supported self-management for children and young people (published, [Saxby et al., Patient Educ. Couns., 2020](#)) [9]

A rigorous new interdisciplinary method of concept analysis was also developed for the purposes of this thesis (two manuscripts in preparation for publication 2020).

Together, the outputs of this research program conditions (i.e. the three peer reviewed journal articles [7-9], the three journal articles in preparation for publication, and the two versions of a printed book [[5, 6](#)]) form an interdisciplinary framework for supported self-Management for children and young people with chronic. Several key differences between supported self-management for children/young people and chronic condition self-management for adults were identified. Supported self-management was found to be a layered and multidimensional process – which supports the complexity and interrelatedness of the attributes, antecedents and consequences of the concept. Moreover, this research found that the presence of the developmental trajectory throughout childhood and adolescence requires a child-centred and individualised, triadic, and an adjustable and responsive approach.

Through the encouragement of children's and young people's lifelong active participation in supported self-management, which begins at the time of diagnosis, the research findings have the potential to influence the quality of life of children and young people. The research findings may also assist in improving interdisciplinary paediatric healthcare practices; in turn, leading to improved transition processes from paediatric to adult healthcare services.

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