



# How children and young people self-manage their chronic illness: Giving children a voice through photo-elicitation

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## Introduction

Chronic illness in children can require complex treatment and intervention which can impact on the normal trajectory of their development (Venning et al. 2008). Research suggests that the cumulative toll on children and their families is often high in social, psychological and economic terms (Kepreotes et al. 2010, George et al. 2011). However, the lack of focus on children in middle childhood (age 7-12 years) means that there is little contemporary, robust knowledge about how children of this age experience chronic illness, symptoms, medication and health interventions

This study aimed to explore children's understanding and perception of their chronic illness and how this shapes their lives.

## Methodology and Methods

A qualitative, participatory methodology that acknowledged the children's agency underpinned the study. We used photo-elicitation (photographs and interviews) to build knowledge grounded in the children's experiences.

Forty-five children (6-12 years) from different diagnostic groups were recruited from hospital-based and support group settings in England, Tasmania and New Zealand.

The children were given digital cameras and asked to record aspects of their lives and chronic illness. Children also had the option of including pre-existing photographs into the study. The researchers then undertook audio-recorded interviews that were guided by the photographs that the children wished to talk about.

Most interviews were undertaken in the child's home.

## Findings

**Brokering** was a key concept that underpinned the children's ways of accommodating the demands of chronic illness.

The children focused on **'I can.....'** rather than **'I can't.....'** and their photographs reflected them engaging in a range of different activities from sport to drawing, playing with their pets and spending time with friends and family.

The children actively **foregrounded** their achievements and focused on 'getting on' with being a child. Whilst this was not always easy, the children generally talked about enjoying life.

There was evidence of much resilience, although this took effort and imagination from the children and their families. The children's parents/carers provided an important role in supporting the children's ability to self-manage their illness.

The children were able to talk with confidence about certain aspects of self-management and they used creative strategies to be 'like other children'. Many were adept at negotiating risks and benefits in order to 'fit in'. Chronic illness – to a greater or lesser extent – was 'always there', but it was often successfully **backgrounded** through careful planning. Treatment and medication were dealt with by developing practices that made it easier to deal with.

## Conclusion

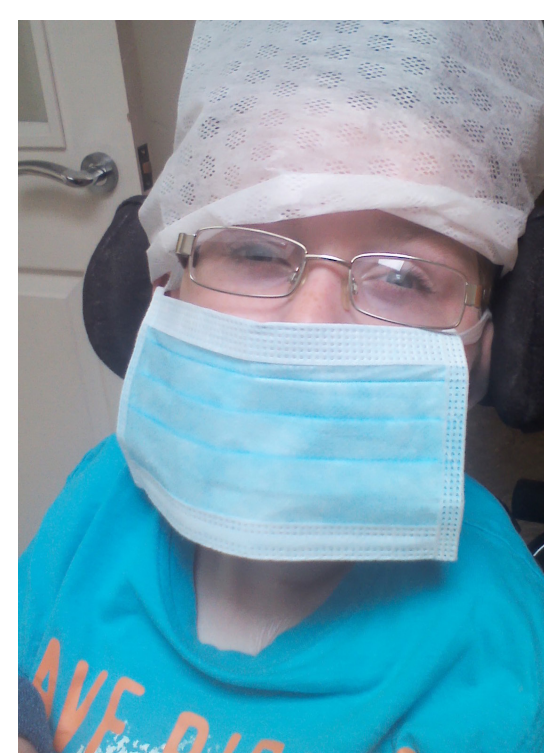
Brokering and self-management were evident in the stories children told about themselves. The use of photo-elicitation gave the children control over those facets of their lives they wanted to discuss and share with the researchers. We found it a useful tool to discover those things that were important to the children and how they were active in ensuring that they could say 'I can.....'

## Data analysis

We undertook interpretative thematic analysis of the interviews and content analysis of the photographs.



**"My name is Andrew. I am 8 years old. I have a good life"** (Boy, 8yrs, New Zealand)

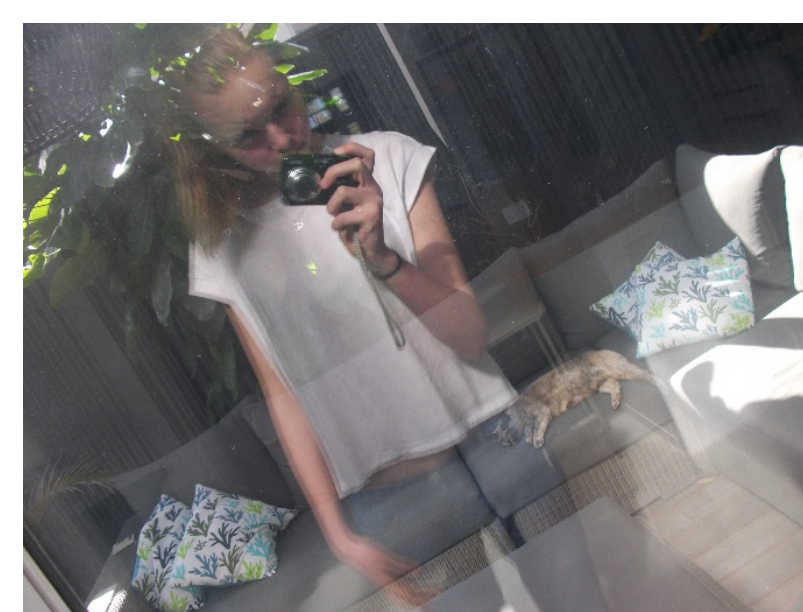


**"This is my catheter and I can do it all by myself now"** (Boy, 7yrs, Australia)



**"I can ride my bike to school"** (Boy, 9yrs, UK)

**"..I think it is really important if you are really sore, you can take your mind off the pain by watching something"** (Girl, 11yrs, New Zealand)



**"... parties are ...really hard.. everyone has really nice food.. if you can't eat that food you feel kind of excluded. I usually take food to parties in case, you get quite used to it"** (Girl, 12yrs, New Zealand)



**"That's my dog Barney, it's like they know. One time I had a bleed and it ached. He licked it and it was like he knew"** (Boy, 12 yrs, Australia)

## References

<sup>1</sup>Venning A. et al. (2008) Understanding young peoples' experience of chronic illness: a systematic review. *Int. Jnl. of Evidence-Based Healthcare* 6, 321-336. <sup>2</sup>George A. et al. (2011) Financial implications for parents working full time and caring for a child with chronic illness. *Australasian Jnl. of Early Childhood* 36, 131-140. <sup>3</sup>Kepreotes E. et al. (2010) The experience of parenting children with chronic health conditions: a new reality. *Jnl. of Nursing & Healthcare of Chronic Illnesses* 2, 51.

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