

"It's not who I am": Children's experiences of growing up with a long-term condition in England, Australia, and New Zealand

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Young children's experiences of growing up with a chronic illness



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What is it about?

This study brings the children's perspectives and opinions about growing up with a chronic illness to the fore. It explores how they define and see themselves as children first and foremost and choose not to be defined by the symptoms and challenges of their illness. They know that they are different to their friends who do not have a chronic illness but they state that their illness is 'not who they are'.

Why is it important?

Most studies that ask children what it like to grow up with a chronic illness ask adolescents/older children. Our study focused on younger children.

This paper is important because it focuses on the children rather than their conditions and it also reflects the perspective of children in England, Australia and New Zealand. Most other studies focus on a single condition and are focused on one country.



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This was a great study to work on, not least because it involved working with friends and colleagues from Circle, an international group of children's nurses whose mission is to improve the lives of children and families. It was also a pleasure to write as everyone worked so hard to make it happen.

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