

# The psychosocial impact of congenital hand differences on children

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## INTRODUCTION

Living with a congenital hand or upper limb difference (CHULD) is a known source of stress for children and their family. Research addressing specific psychosocial issues identified by individuals living with a CHULD, such as stress associated with appearance or functional impairment is scarce, and that which does exist is conflicting. The aim of this study was to explore the psychosocial impact of living with a CHULD, from the perspective of children and their parents.

## METHODS

Children aged 5-16 years and their parents were recruited from the Australian Hand Difference Register (AHDR). In-depth, semi-structured interviews were conducted with eight parent-child dyads. Parents and children were interviewed sequentially with separate interview guides. Discussion focused on the influence of CHULDs on the child's function, perception of appearance and social interactions, and positive aspects of having a CHULD. Open format interviews allowed spontaneous emergence of relevant themes, followed by guided questioning. Thematic analysis was undertaken with phenomenology as a methodological framework.

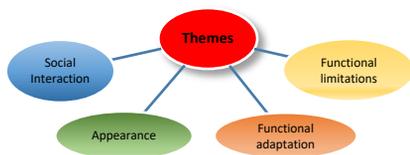


Fig 1. Key themes: Appearance was the most prominent theme identified, with a significant variation in responses. All children described their hand appearance as either 'normal', 'different' or 'the same' as others. Less than half the children wished to change their hand appearance because it made them feel 'different'. An equal number accepted their hand and its uniqueness. Three children were particularly proud of their scars.

## RESULTS

Eight interviews were carried out with five girls and three boys (mean age 9.6 years), along with eight parents. Interview duration ranged from 12-96 minutes.

Key themes identified following data analysis included: *functional limitations*, *appearance*, *social interaction* and *functional adaptation*. These are represented in Figure 1. Verbatim quotes are listed below, with pseudonyms used for all participants.



Fig 2. Amity 8mo, symbrachydactyly

### Results: Verbatim Quotes

#### Theme 1: Functional limitations

*'Knowing that I can't wear jewellery, or like, do certain things with it, and can't write for a long period of time, like during school, it does kind of affect me, 'cause I'll have to stop writing and catch up on the work later on, like for homework.'* Beth 13yo, brachydactyly

*'...the problem is I write for twenty minutes and then I just can't write because it hurts so much. Apparently my muscle back here is not as strong, so I can't hold things for long.'* Declan, 11y, distal arthrogyrosis

#### Theme 2: Appearance

*'It's more like, I guess, more chubbier than other people's hands, but everyone is different. But when it comes to wearing jewellery I'll find it hard because it won't sit properly, or the extra fat here will show more. So I find it a bit hard.'* Beth 13yo, brachydactyly

Researcher: *'So what do you like about your hand?'*

Kate: *'That I'm different, that I'm not the same as everyone else. (.) I kind of like the scars.'* (laughs) Kate 10yo, triphalangeal thumb

#### Theme 4: Functional adaptation

*'...lots of people are just intrigued and they're like, I dunno, just fascinated by the way he finds a way to do stuff. I'll buy him a chocolate bar in the supermarket, and he'll walk over to the wall and prop himself up on the wall to eat the chocolate bar...And people are like 'oh what's he doing?' and I'm like 'well, when there's a will there's a way, and Sam will find a way if he can't get the help.'* Mother of Sam, 7yo, arthrogyrosis multiplex congenita

#### Theme 3: Social Interaction

*'She was very self-conscious...she hates trying to explain it, she'd much rather just try to blend into the background. So that's probably the major thing with the surgery. Everyone wants to know what happened and why.'* Mother of Kate 10yo, triphalangeal thumb

## DISCUSSION/CONCLUSION

Despite the stress children with CHULDs face, they generally cope well, finding ways to adapt both socially and functionally. CHULD appearance bothers most children, however the associated degree of psychosocial impact is variable, and is not proportional to severity. Some children wish to change their hand appearance in some way, while others accept or even like their hand appearance, and are particularly proud of their scars. Writing causes the greatest degree of frustration for children with CHULDs, yet children prefer to remain independent, which encourages functional adaptation. Unsolicited questioning, especially around the time of surgery creates significant stress for children, who become self-conscious when forced to explain their CHULD to others. Yet this stress is mostly transient, and children develop planned responses as a positive coping mechanism. Parents and friends are important sources of social support for children with CHULDs, however parents are sometimes unaware of the psychosocial impact of the CHULD on their child. Future qualitative research should thus involve children as active participants. This study provides empirical evidence that paediatric hand surgeons can utilise to improve existing support offered to children and families.