Conclusion:
Better health care is needed and change can be supported by:
- Providing enhanced training and education for health professionals regarding communication skills and implicit bias
- Developing better supports for parents and young people, especially peer support and specialist psychological support
- Championing bodily autonomy, recommending delaying appearance based surgical intervention until a young person can have agency to decide for themselves
- Challenging the norm, and accepting that difference is part of a diverse society
- Always including people with a VSC in service development and delivery
- Ongoing research supporting active change

Reseach originality:
This research is original and innovative in three ways – it demonstrates close collaboration between activists and academics through all stages of the research design and conduct; it provides a unique 360-degree perspective integrating the views of clinicians, parents and young people; and it fills a gap in the literature by capturing the voice of current young people living with VSC.

Background:
People born with a variation in sex characteristics or Difference of sex development (DSD/VSC) face the challenge of having atypically sexed bodies. This qualitative study recruited young adults with DSD/VSC; parents of children with VSC; and health professionals. This study was conducted in collaboration with the Intersex trust of Aotearoa/New Zealand (ITANZ).

Aim:
To identify key themes regarding participants’ experiences of decision-making in the health care setting.

Methods:
Research participants N=50
- Young people
- Parents
- Health professionals

Demographics:

Findings:
Four common elements across the three participant groups influenced decision making: communication, bias, norms and support
There were two additional themes for each participant group.
- Health professionals: recognition of the past and expectations
- Young people: bodily autonomy and identity
- Parents: what’s right and future worries

All these elements underpinned the overarching element of trust. These elements of influence could be experienced as either positive or negative depending on the circumstance (e.g. the way information about diagnosis was communicated could be either positive or negative).

Decision making process using research elements influencing decision making

References

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