



AutismCRC

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The Cooperative Research Centre for Living with Autism (Autism CRC)

The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people on the autism spectrum.

autismcrc.com.au

A note on terminology

We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, when speaking of adults we use the terms 'autistic person', 'person on the autism spectrum' or 'person on the spectrum'. The term 'autistic person' uses identity first language, which reflects the belief that being autistic is a core part of a person's identity.

Autism Spectrum Disorder (ASD) is diagnostic terminology used by the healthcare sector, and is used in the context of a person being 'diagnosed with Autism Spectrum Disorder'.

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Background

Autism is a neurodiverse state of being of which people recognised formally as autistic can experience challenges with social communication and integration of sensory stimuli, as well as having strengths with memory, complex thinking, and pattern recognition¹. Many autistic adults experience a poor quality of life (QoL)². QoL is a documented priority and focus of the autistic community, who would like to see a greater focus on QoL in therapeutic supports as opposed to deficits³.

QoL is defined by the World Health Organisation (WHO) as an individual's perception of their position in life, in the context of the culture and values system in which they live, and in relation to their goals, expectations, standards and concerns^{4, 5}. A significant body of research has focused on "health related QoL" (HRQoL), with a focus on physical, psychological, and social functioning⁴. While this approach has some merit, it seems inadequate in operationalising the WHO definition which highlights the importance of social, physical, and mental wellbeing in reference to an individual's context and personal values, a context likely to be of particular importance to autistic individuals.

A systematic review found that 14 QoL tools have been applied in research with autistic adults, none of which were developed specifically for use with the autistic community⁶. While the World Health Organisation Quality of Life Brief^{4, 5} (WHO QoL-Brief) has recently been adapted for use with autistic people⁷, to date no QoL tool has been developed which is underpinned by comprehensive examination of the construct of QoL from the perspective of autistic individuals themselves.

Given the unique characteristics and challenges experienced by autistic people, in order to be valid, it is important that both the operationalisation and measurement of the construct of QoL are informed by the perspective of autistic people. There is a need for increased investment in participatory research, or research co-produced with autistic individuals. Research informed by the insider perspective, or "expertise by experience" ensures that the right questions are asked, leading to new understandings consistent with the lived experience of autism. This research project subsequently aimed to co-produce and develop a pilot autism-specific quality of life assessment for use with autistic adults. Specific objectives were to:

1. Development of an autistic steering group overseeing all aspects of this research, enhancing both the impact of the project, and its relevance to the autism community.
2. Phase 1 – Knowledge Inquiry
 - Develop content validity identifying aspects of ‘life story’ autistic adults perceive most important in contributing to QoL
 - Develop construct validity, identifying viewpoints of autistic adults and importance to their QoL.
3. Phase 2 – Assessment Development and Implementation
 - Assess tool content validity and clinical utility of autism QoL assessment prototype from autistic adults and health care professionals’ when using the tool with autistic adults.

Research Design and Methods

This research project included three mixed methods empirical community studies involving autistic adults and healthcare professionals. Ethical approval was obtained through Curtin University Health Research committee (HREC approval number 2017-0865). Before commencement, a steering group of five autistic individuals with an array of skills and experiences was recruited. The steering group was involved throughout the duration of the research journey (see Appendix A, table 1 for record co-production) including development of interview and focus group questions, feedback on collected photo voice photos and development of clinical utility and content validity survey. All group members were paid for their time and involvement. In preparation for the project, the Australian Longitudinal Study of Adults with Autism (ALSAA) data was analysed from the special interest category of ALSAA's “adult self-report questionnaire”. This analysis provided background to this research, including identifying common areas of special interest and a brief insight into its relationship to QOL. Interview questions considered the impact of special interests on QOL areas such as relationships, employment, mental health, and physical health. The first empirical study involved 29 autistic individuals from the Australian community aged between 18 and 55 who participated in interviews (face to face, online, text) to identify common areas of importance to their quality of life. Thematic analysis identified five main themes, important to and impactful upon autistic adults’ QoL. Qualitative data analysis involved an iterative approach by multiple researchers to identify emerging themes and sub-themes.

The findings were used to guide the second empirical study, which sought to gain further in depth understanding of QoL from the perspective of autistic adults. Participatory research included the use of photovoice to capture autistic adults' QoL experiences, and to determine factors that contribute to their QoL. A total of 15 autistic individuals aged between 18–55 were recruited across Australia to capture digital images that related to their meaning and understanding of factors that contributed to their QoL. All participants took part in a follow up interview and shared up to 20 photos they felt were related to their QoL. Follow up focus groups were then utilised to provide opportunity for participants to describe the meaning and themes associated with their photo. Thematic analysis was utilised by the research team to determine the description and meaning of each photo.

The third empirical study involved utilising the dominant themes from study 1 and 2 to create a pilot autistic quality of life self-report tool for use with autistic adults. The pilot tool consisted of 111 factors related to autistic quality of life and was created in collaboration with the autistic steering group. The pilot tool consisted of five areas of perceived autistic quality of life, including personal experiences, mind and body, activities, supports and relationships, and environment. To determine the content validity of the pilot autistic quality of life assessment self-report measure, an online survey of 14 autistic adults between the ages of 18 and 55, living in Australia was utilised. To further determine the content validity and clinical utility of the pilot assessment tool, the perspective of health clinicians working in Australia with autistic adults was sought. 15 health clinicians provided feedback on content validity and clinical utility. Template analysis was used to analyse survey responses.

Findings

The findings from this project are presented in a series of appendices in their original format. These appendices are embargoed whilst they undergo peer review and/or assessment, but will be made available in the project Final Report on the Autism CRC website once the embargo lifts. The findings from study 1 appear in Appendix B which is the precursor to a journal publication titled “Untangling the web of life: An exploration of quality of life as identified by autistic adults by Kuzminski et al. The manuscript describes the importance of the identified themes from autistic individuals contributing to QoL including activities and routines; relationships, socialisation and supports; mind and body; personal experiences; and the environment around me. The findings from study 2

appear in Appendix C is the precursor to a journal publication titled “A picture tells a 1000 stories using photo voice to capture quality of life in the Australian autistic community” by Kuzminski et al. Over 289 photos were collected and analysed. The manuscript describes the analysis of participants’ photos resulting in the emergence of dominant themes summarising areas most influential upon QoL. Five main themes were identified, including tasks and activities, needs, individual identity, environment, and emotions and experiences. These themes do not occur in isolation from one another, but intersect with some ingredients of quality of life impacting or influencing others. The findings from study 2 were also presented as an online photo galley presented by Autism CRC and launched through YouTube in November 2020

<https://www.youtube.com/watch?v=8H2Arlbe3B0> (see Appendix D for sample of photos presented by Autism CRC for online gallery).

Appendix E is the precursor to a journal publication titled “Measuring Autistic Quality of Life from the Ground Up: Assessing Content Validity and Clinical Utility of a New Autistic Quality of Life Tool” by Kuzminski et al. The manuscript presents the content and clinical utility of the pilot autistic QOL assessment. Findings identified four (4) themes including acceptable, appropriate, practicable and relevance of content.

Limitations

The study involved Australian autistic individuals recruited over a twelve month period as well as health clinicians. The time frame, sample size and geographical specificity limits generalizability of this research study. The notion that QoL begins to deteriorate for those aged over 55 is problematic and the decision to limit recruitment at this age is in opposition to current research with many autistic individuals being diagnosed in later life. It is felt that recruitment is likely to have been impacted by participant burden in the context of the onset of the COVID-19 pandemic during the later stages of the project. It was also difficult to recruit health clinicians to participate in the content validity focus groups with feedback sought via a survey instead. As a result of COVID-19 and difficulty accessing participants, a request was made to Autism CRC to examine the Australian Longitudinal Study of Adults with Autism (ALSAA) data on relationships. A delay occurred in accessing the data and the team are still progressing the analysis with view to delivering a finalised manuscript for publication by October 2021.

Implications for Research and Practice

This research project has taken a first and important step towards developing a pilot assessment tool of quality of life. This project delivers insight into the domains of QoL most relevant to autistic adults, and the facilitators and detractors of their unique QoL. The main finding of this project is that for autistic adults QoL is unique and is often impacted by factors other than those measured in traditional QoL assessments. Autistic individuals' ability to pursue passions, safe and meaningful relationships is paramount, and tools should be designed to support finding their unique place in the world. This new knowledge has informed a pilot QoL tool drawn from an autistic perspective, enabling for the first time, meaningful measurement of the construct within the autistic community. The co-produced nature of this research provides opportunities to employ and further develop research methodologies. Co-produced research, whilst increasingly common, is a relatively recent approach to disability research. The development of methods enabling co-production are important to future autism research, and position autistic individuals as experts by experience

Key Recommendations

Co-production should be at the heart of all research with and for the autistic community. Photo voice appears to be an effective mechanism in fostering and enabling co-produced dialogues, facilitating a sharing of power between researchers and participants. The autistic pilot quality of life tool developed through this research project has identified important areas for further refinement and development that requires co-producing with autistic individuals.

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Our values



Inclusion

Working together with those with the lived experience of autism in all we do



Innovation

New solutions for long term challenges



Evidence

Guided by evidence-based research and peer review



Independence

Maintaining autonomy and integrity



Cooperation

Bringing benefits to our partners; capturing opportunities they cannot capture alone



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