Abstract:

Purpose:
This paper describes the possible impact of normalisation on perceptions of quality of life, and the impact of this association on the research to date. This commentary reflects on the implications of limiting quality of life research to autistic people who are perceived to be 'more able'.

Design/methodology/approach:
This commentary discusses the implications of undertaking quality of life research in the field of autism.

Findings:
This commentary argues for further consideration of the autistic voice in quality of life research. Researcher epistemology and life experience, including experience of autistic people are examined, in terms of how quality of life might be perceived and attributed. Further participatory research around quality of life of autistic people, including those with a learning disability, and engagement with a variety of autistic people, are called for.

Originality/value:
This commentary suggests that existing definitions of quality of life, founded on principles of normalisation, may not be completely applicable to autistic people, and that new ways of both defining and measuring quality of life might be needed

Introduction

The Quality of Life [QoL] of autistic people has been frequently explored and is of increasing interest in academic literature (e.g. van Heijst and Guerts, 2015; Kim 2019). The study by Smith *et al.*, presents a unique contribution to this field through examination of the QoL of autistic people with a learning disability; a group that is currently underrepresented in the literature. The authors comment on the potential difference in how autistic people conceptualise their QoL in comparison to their non-autistic counterparts. This commentary seeks to explore the implications of studying the QoL of autistic people, including autistic people with a learning disability.

Identity first language (i.e. autistic person) will be used throughout, given the writer of this commentary identifies as an autistic academic, and recent findings from the British autistic community display a preference for identity first language (Kenny *et al.*, 2016).

The influence of normalisation upon QoL

The authors of this article argue that QoL is a global and multidimensional concept, with over 44 definitions reported to be found. Although it is reported that QoL is a complex concept, it remains unclear as to what extent neurotypical definitions of a 'good QoL' may be applicable to an autistic person. It remains unknown if autistic people, or in fact disabled people, have been involved in shaping the narrative of defining a 'good QoL', including that used in academic research. Given historical and ongoing stigma experienced by disabled people (Goffman, 1963), in particular autism and learning disability, it is unclear how much the definition of a good QoL has been constructed in a way sympathetic to the views and lived experience of autistic people. Rather, the definition of a 'good QoL' may originate more from the ideas of able-bodied, neurotypical people, in particular academics.

With regard to autistic people who have a learning disability, the concept of QoL is also closely associated with, and derived from, the ideology of normalisation (Nirje, 1969). Improving the QoL of disabled people, including autistic people, has been a key element in service provision since scandalisation of poor conditions found in asylums (Goffman, 1961) and subsequent legislation (e.g. Community Care Act, 1990). However normalisation as an ideology was conceptualised and disseminated by able-bodied academics, and not disabled people (Walmsley, 2001). This power imbalance has led to critiques of normalisation in relation to autistic people (Milton and Moon, 2012; Chown *et al.*, 2017; Waldock, 2018a) and those with a learning disability (e.g. Szivos-Bach, 1993) and a move towards co-production and participatory work, especially in regards to autism (e.g. Chown *et al.*, 2017). In spite of this, the extent to which these reflections have been addressed in research examining the QoL of autistic people remains unclear. With the current move towards meaningful inclusion of, and engagement with, autistic people and people with a learning disability in research, this commentary calls for future QoL research to be sensitive to the history of conceptualising QoL and the benefits of co-production on research findings.

Measuring Quality of Life - Tools and Methods

Given that QoL may need to be defined differently in this population, how might it be measured and assessed? Firstly, what tools might be useful and secondly, might there be changes in the ways in which information on QoL is collected?

Firstly, the tools used to measure QoL need to be scrutinised in relation to their suitability for the autistic population. This is of particular note given Smith *et al.*'s suggestion of autistic people conceptualising their QoL differently to non-autistic people. Smith *et al.* used the ComQoL (Cummins and Lau, 1997), which has been used previously in studies examining populations with a learning disability (e.g. Verri *et al.*, 1999; McGillivray *et al.*, 2009). Both these studies excluded autistic people with a learning disability from their samples and it remains unreported if the ComQoL is validated for use on autistic people. This is key when considering nuances in differences of neurology impacting an individual's life experience, which might be missed. Examples include how social time is spent e.g. a preference for spending time with people on a one-to-one basis instead of in large groups (Johnson and Hanes, 2018) and activities which are specific to disabled people, e.g. (self-) advocacy groups and meetups of autistic people (Kim, 2019).

Another perspective to consider is whether sufficient space and sensitivity were given to reflecting on the socio-cultural contexts when the tools were administered. These tools are often completed by professionals, ether academics or support staff, especially in regards to autistic people, where self-report is not always viewed as a reliable manner of collecting data surrounding an individual's QoL (van Heijst and Guerts, 2015). The impact of sensitivity to the socio-cultural context was first argued by Robertson (2009) in relation to autistic QoL. Crude notions of 'normalised' people (i.e. people who behave in accordance with socially accepted norms and meet socially accepted milestones) having higher QoL may still prevail; in essence this refers to individuals doing activities that are valued by society, and also perceived to be benefitting QoL. These activities are considered to be of high value by wider society.

Some tools may be considered to be objective, for example collecting data regarding an individual's social network using a rating scale. Data collected by such tools may have to cross different epistemological stances (e.g. a different understanding and knowledge of the world due to differing lived experience) (Milton, 2012a) when going through a socio-cultural filter (such as attitudes towards the individual or group of people, e.g. autistic people). Different personal values also need to be considered, for example extraverts are energised by socialising in large groups, thus valuing them differently to introverts who might become exhausted by such social environments. It remains uncertain the extent to which Smith *et al.*, accounted for this in their methodology or findings.

The importance of social interaction

One of the key findings from the authors is the importance of social interaction within the QoL of autistic people with a learning disability, and the mixture of positive and negative themes surrounding social interaction. The importance of social interaction to QoL challenges assumptions that might be held regarding the sociability of autistic people, notably the myth that autistic people universally have no wish for friendships and/or relationships. This echoes the findings of Johnson and Hanes (2018) when exploring autistic people's social networks. These findings also parallel Robertson's (2009) discussion, where he explains that autism (and the subsequent impact on QoL) is always framed in a negative manner. The mixed nature of responses surrounding social interaction furthermore challenges the assumed homogeneity of autistic people and their preferences. This is crucial to understanding the autistic people with whom we work, given the internal nature of autism (Williams, 1996) and how this intersects with other elements (e.g. gender, sexuality, ethnicity). Key to a person-centred approach is the notion that getting to know and learning about individual autistic people is essential to be able to best support and enable them (Milton, 2012b). Such an approach is central to both *Valuing People Now* (2009) and *Think Autism* (2014), which are both policies impacting and influencing the support that might be given to autistic people in the community and in services.

Autistic people with a learning disability

Autistic people with learning disability are often excluded from studies investigating QoL (Kim, 2019) and both studies in the fields of autism and learning disability beyond QoL research (with one example given in Waldock, 2018b in regards to talking therapies for autistic people). Smith *et al.*, found the QoL of their sample to be lower in comparison to their non-autistic counterparts; further investigation is required to confirm which domains are lower in autistic people, given some domains tend to be more highly researched than others (Kim, 2019). Smith *et al.* call for further research specifically focusing on autistic people with a learning disability.

However consideration needs to be given to methodology when focusing on this particular group. The authors use one-to-one spoken interviews in this study, which excludes autistic people with a learning disability who do not use spoken language to communicate. As not all people with a learning disability, nor autistic people, use spoken language as their primary means of communication, alternative means of engaging with this group (for example through a creative or visual method as described in Nind, 2008) is vital to ensure the gaining of data unmediated by others' perspectives.

Although Smith *et al.* made use of a focus group, it remains unclear how much the influenced the development of the methods used. Further research might benefit from an explicitly co-productive approach with autistic people, including those with a learning disability. This could include development of research proposals and research questions, the use of advisory groups at various stages of the project and co-analysis of the data collected.

Conclusion

There are many aspects which need to be considered when conceptualising and measuring the QoL of autistic people. Consideration of who defines 'good QoL', and the influence of what is regarded as normal, need to be taken into account when exploring QoL in marginalised groups, including autistic people and people with a learning disability. Smith and her colleagues pave the way for further investigation of the QoL of autistic people who have a learning disability. Various methodological aspects need to be recognised in the design of such studies, including the epistemological stance of the researcher, capacity for co-production and co-researching, the measurement tools used and their sensitivity to contexts impacting QoL in autistic people.

References:

Chown, N., Robinson, J., Beardon, L., Downing, J., Hughes, L., Leatherland, J., Fox, K., Hickman, L. and MacGregor, D. (2017). "Improving research about us, with us: a draft framework for inclusive autism research", *Disability & society*, Vol. 32 No. 5, pp.720-734.

Cummins, R.A. and Lau, A.L.D. (1997). *Comprehensive Quality of life scale-Intellectual/Cognitive Disability. 5th Edition. Manual*. School of Psychology, Deakin University: Deakin University.

Goffman, E. (1961), *Asylums: Essays on the Social Situation of Mental Patients and other Inmates*. New York: Random House.

Goffman, E. (1963), *Stigma: Notes on the management of spoiled identity*. London: Penguin Books.

Department of Health. (2009), *Valuing People Now: A New Three Year Strategy for People with Learning Disabilities*. London: Her Majesty's Stationery Office.

Department of Health. (2014), *Think Autism: an update to the government adult autism strategy*. London: Her Majesty's Stationery Office.

Johnson, J. and Hanes, R.R. (2018), "Exploring the Social Experience of Adults on the Autism Spectrum: Views on Friendships, Dating and Partnerships", *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, Vol. 1 No. 5.

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C. and Pellicano, E. (2016), "Which terms should be used to describe autism? Perspectives from the UK autism community", *Autism*, Vol. 20 No. 4, pp.442-462.

Kim, S.Y. (2019), "The experiences of adults with autism spectrum disorder: Self-determination and quality of life", *Research in Autism Spectrum Disorders*, Vol. 60, pp.1-15.

McGillivray, J.A., Lau, A.L.D., Cummins, R.A. and Davey, G. (2009), "The utility of the personal wellbeing index intellectual disability scale in an Australian sample", *Journal of Applied Research in Intellectual Disabilities*, Vol. 22 No. 3, pp.276-286.

Milton, D. and Moon, L. (2012), "The normalisation agenda and the psycho-emotional disablement of autistic people", *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, Vol. 1 No. 1.

Milton, D.E. (2012a), "On the ontological status of autism: the 'double empathy problem'", *Disability & Society*, Vol. 27 No. 6, pp.883-887.

Milton, D. (2012b), "So what exactly is autism?", *AET Competence framework for the Department for Education,* available at: http://www.aettraininghubs.org.uk/wp-content/uploads/2012/08/1_So-what-exactly-is-autism.pdf (accessed 8th February 2019)

Nind, M. (2008). *Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges*. National Centre for Research Methods, available at: http://eprints.ncrm.ac.uk/491/1/MethodsReviewPaperNCRM-012.pdf (accessed 13th February 2019)

Nirje, B. (1969), "The normalization principle and its human management implications", *Changing patterns in residential services for the mentally retarded*, pp179-195.

Robertson, S.M. (2009), "Neurodiversity, quality of life, and autistic adults: Shifting research and professional focuses onto real-life challenges", *Disability Studies Quarterly*, Vol. 30 No.1.

Szivos-Bach, S.E. (1993), "Social comparisons, stigma and mainstreaming: The self esteem of young adults with a mild mental handicap", *Mental Handicap Research*, Vol. 6 No. 3, pp.217-236.

Verri, A., Cummins, R.A., Petito, F., Vallero, E., Monteath, S., Gerosa, E. and Nappi, G. (1999), "An Italian–Australian comparison of quality of life among people with intellectual disability living in the community", *Journal of Intellectual Disability Research*, Vol. 43 No. 6, pp.513-522.

van Heijst, B. F., and Geurts, H. M. (2015). "Quality of life in autism across the lifespan: A meta-analysis", *Autism*, Vol. 19 No. 2, pp.158-167.

Waldock, K. E. (2018a), "An exploratory study of attitudes towards autism among church-going Christians in four Protestant Churches in the South East of England", unpublished MA dissertation, University of Kent.

Waldock, K. E. (2018b), "Some of the challenges associated with offering 'talking' psychological therapies to autistic people and potential solutions", unpublished MA essay, University of Kent.

Walmsley, J. (2001), "Normalisation, emancipatory research and inclusive research in learning disability", *Disability & Society*, Vol. 16 No. 2, pp.187-205.

Williams, D. (1996), *Autism--an Inside-out Approach: An Innovative Look at the Mechanics of 'autism' and Its Developmental 'cousins'*. London: Jessica Kingsley Publications.