Quality of life and autistics: the critical roles of social support and subjective well-being

Steven Kapp
Introduction

- Autism mainly diagnosed by social communication
- Social interaction occurs *between* people
- Dynamics with others hugely affect autistics’ lives

Talk highlights roles of social support and subjective well-being for autistics’ quality of life (QoL)
  - Objective QoL: adaptive functioning in major domains
  - Subjective QoL: personal judgment, feelings about life
Parental support:

Language acquisition

- Responsive parenting especially helps autistic children performing at lower levels to develop language\textsuperscript{1-11}

Autism acceptance

- Parental autism acceptance\textsuperscript{12-15} and positive emotions toward child\textsuperscript{16} are \textit{not} associated with child symptoms, disability

- Parental autism acceptance \textit{is} associated with better parent-child reciprocity\textsuperscript{17,18} and relationship\textsuperscript{19,20}
School support:

Educational inclusion

- Inclusive learning settings are associated with better functioning for autistics\(^{21-23}\), especially those with delays\(^{22}\)

Social (peer) inclusion

- Autistic youth with more social attempts and skills tend to suffer more victimization, stigma, distress\(^{24-27}\)
Systemic support in adulthood

- Among autistic young adults transition from secondary school tends to produce relatively more struggle for those *without* intellectual disability\(^{28-30}\)
  - More often lose services\(^{31}\)
- Services\(^{32}\) and employment\(^{33}\) tend to improve functioning
Subjective well-being

- Children and adults who perform or are perceived as higher skilled or functioning tend to judge their autism as more severe and endorse more anxiety and depression\(^{34-39}\)
- Pattern may relate to victimization and mistreatment
  - Autistic adults report quality of life may relate to social support, not autistic traits\(^{40}\)
  - Similarly, social support tends to weigh more heavily in self- than parent report of autistic adults’ quality of life\(^{41}\)
Implications

- No direct relationship between autism symptoms and functioning
  - Importance of social context
  - (Some) autism symptoms can have neutral or positive effects on well-being
- Importance of understanding and sensitive responding to autistic people, acceptance, inclusion
References


References (continued)


References (continued)


References (continued)


Acknowledgments

- Seminar team for invitation and funding
- Ginny Russell and the Exploring Diagnosis team at the University of Exeter for further funding and comments
- The Wellcome Trust for funding Exploring Diagnosis
- Healthcare Transitions Research Network for inviting me to contribute article
- Connie Kasari and the Health Resources and Services Administration of the U.S. Department of Health and Human Services for funding time on the article
Q & A

- Questions?
- Comments?
- Suggestions?

For further contact: s.k.kapp@exeter.ac.uk