



Becoming an autistic autism researcher

Carole Kelly

*Professional Doctorate in Health Research (DHRes)
University of Hertfordshire, School of Health and Social Work*



Agenda

1. Terminology
2. A bit about me...
3. My qualitative research project so far...
4. The double empathy theory
5. What it has been like to be a researcher with 'insider knowledge'

Terminology

- Identity-first language is being used rather than person-first language, e.g. the term 'autistic person' instead of 'person with autism', as this is the terminology that my participants prefer, as do the majority of the autistic community (Kenny et al. 2016)
- 'Autism' is being used as shorthand for 'autism spectrum condition' without additional learning disability (LD)
- The terms 'woman' and 'mother' include individuals whom society generally perceive to be fulfilling these social roles, and include non-binary identities

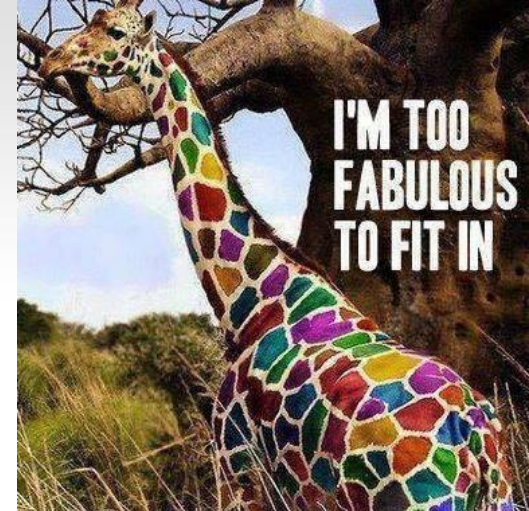
A bit about me...

- Throughout my life, I always felt 'different', that I did not belong, but thought it was due to my traumatic childhood
- Age 11, I had already attempted suicide, dropped out of school, and started psychoanalysis
- Age 17, I met my husband – he encouraged me to talk and, for the first time, express my feelings
- Work as an senior scientist at UK Health Security Agency (formally Public Health England) since 1996
- BSc (Hons) degree in Biology with the OU
- MSc in Medical Microbiology with University of Westminster
- Currently work on HIV and COVID-19
- Many bouts of depression, anxiety, panic attacks and social phobia.....
- Aged 42, finally had my son Leon
- Leon diagnosed with autism and ADHD at age 4
- At 48, I did a PGCert in Autism and AS at SHU
- At 50, I was diagnosed with Autism and ADHD
- At 51, I started my DHRes at UH, now in 5th year



Autism

- Autism is a complex neurodevelopmental condition - lifespan prevalence of 1% (Brugha et al. 2012)
- Asperger syndrome categorised by WHO in 1992
- Autism diagnoses increased during the last 30 years – but mostly in boys (Brugha et al. 2012)
- M/F ratio was 4:1 (2:1 with LD; 10:1 without); now 3:1 (Loomes et al. 2017)
- Autistic women under-represented in research - clear male-biased understanding by clinicians (Hurley 2014)
- Systematic literature review – the ‘Sense-making narratives of autistic women diagnosed in adulthood’ (Kelly et al. 2022) – synthesised the data of 50 women from nine qualitative studies and four main themes were identified:
 - wanting to ‘fit in’
 - making sense of past experiences
 - developing a new ‘autistic identity’
 - barriers to support
- Women often recognise their own neurodiversity whilst researching autism on behalf of their children (Crane et al. 2018)
- Number of autistic mothers unknown, although hereditary (AWM, 2015)
- Little awareness of autistic motherhood as an identity or social role, only two qualitative studies on mothers



‘The impact of an autism diagnosis on women’s experience of motherhood’

Aim

To explore women’s experience of motherhood following an autism diagnosis in adulthood

Objectives

To describe what experiences or events lead women to seek out, or be sent for, an autism diagnosis in adulthood

To investigate the impact of an autism diagnosis on women’s relationships with their children

To determine how autism diagnoses may affect women’s maternal self-efficacy

To reveal what aspects of women’s own childhood experiences may be reframed following an autism diagnosis

- Inclusion criteria: English-speaking mothers, living in UK, with autism diagnosis received ≥ 18 years
- Advertised invitation in two private Facebook groups for people who identify as autistic - over 100 responses!
- 10 participants, chosen in order they applied and returned consent form
- All had autistic children (some undiagnosed), 2 mothers also had 1 neurotypical child
- Gender: 7 women and 3 non-binary
- Ethnic group: 8 White British, 1 Asian Indian and 1 White Roma
- Semi-structured interviews on MS Teams - relaxed conversational style
- Established an empathetic relationship with each participant
- All participants seemed to find the interview a positive experience

I am looking for mothers who have been diagnosed with autism in adulthood to take part in an exciting new study!

This study is being led by an autistic researcher, and aims to explore how an autism diagnosis in adulthood impacts a woman's experience of motherhood.

- Are you a mother who is 18 years or over?
- Were you diagnosed with Asperger syndrome or Autism Spectrum Disorder, without intellectual difficulties or language delay, in adulthood?



The experience of autistic motherhood has received hardly any attention in research, despite autism being a lifelong condition. Many feel that autistic mothers have been underserved by policies and support services. There is certainly very little awareness of motherhood as an identity and social role for autistic women. This study hopes to bring the voices of autistic mothers to the forefront, as their experiences have historically been unheard and misunderstood.

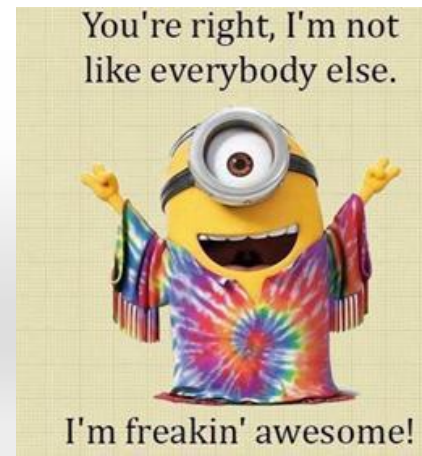
The findings of this research will contribute to a greater understanding and appreciation of autistic motherhood, therefore enabling professionals to better support and accommodate autistic mothers and their families. If you decide to participate, you would take part in an online interview that would last around one hour.

To learn more about this study, please email Carole Kelly at ck17abg@herts.ac.uk. I would be grateful to hear from you. Thank you.

University of Hertfordshire **UH**

The double empathy theory

- During social interaction, there is often a lack of mutual comprehension between people with different perceptual worlds and differing dispositions termed the 'double empathy problem' (Milton 2012)
- The theory challenges the idea that autistic people lack empathy
- It is not only autistic people who struggle to read the intentions and motivations of non-autistic people - the same happens in reverse – communication/interaction is a 'two-way street' (Milton 2017).
- Those with similar dispositions more likely to form connections and rapport (Heasman & Gillespie 2019).
- Having a similar lived experience is more likely to lead to descriptive and insightful accounts (Fletcher-Watson et al. 2018)
- As the participants and I were both autistic, misunderstandings were reduced
- Having a shared identity with my participants meant I was better able to foster trust and rapport
- I was also able to connect with the autistic community to recruit participants and disseminate my findings



Insider knowledge

*“...right from the start, from the time someone came up with the word ‘autism’, the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced.”
(Williams 1996: 14)*

- Having ‘insider experience’ of the phenomena I am exploring, my interpretations of the data and my writing is limited by, and situated by, my knowledge and my experience of the world (Haraway 1988; Willig 2013)
- This knowledge helped me to relate to and understand the experiences and emotions the participants described
- Qualitative work necessitates a researcher's involvement - a completely value-free ‘objective’ perspective is not possible (Willig 2013)
- Developing an awareness of my assumptions and beliefs and using them to enrich my data analysis; rather than thinking of them as biases that need eliminating
- Using curiosity and open-mindedness - listening closely to participant’s narratives and interpreting how they make sense of their lives. Make sure that their interests and views are expressed (Bertilsson Rosqvist et al. 2019)
- Emphasise reflexivity, rather than ‘bracketing’ – being honest about my values and beliefs. Aim for rigor, transparency, constant reflection and learning
- Positionality and reflexivity are critical examinations of how one sees the social world and understands the relationship between content, context and consequences of knowledge arising from the research process (May & Perry 2017)
- Keep a reflexive journal and post-interview field notes to record thoughts, decisions made, critical themes identified during analysis, etc. (Finley 2002)

Acknowledgements

I would like to acknowledge the incredible support and insight I have received in the last five years from my two supervisors, Professor Shula Ramon and Dr Shivani Sharma, during my Professional Doctorate in Health Research programme. It is, and always will be, greatly appreciated.

I would also like to thank my ten participants for their openness and honesty during this study.

References

- Autism Women Matter (2015). A report to the United Kingdom Human Rights Committee: *Human rights violations against parents that are autistic, have an autism spectrum condition*. Retrieved from: [https://tbinternet.ohchr.org/Treaties/CCPR/ Shared%20Documents/GBR/INT_CCPR_CSS_GBR_20656_E.pdf](https://tbinternet.ohchr.org/Treaties/CCPR/Shared%20Documents/GBR/INT_CCPR_CSS_GBR_20656_E.pdf)
- Bertilsson Rosqvist, H., Kourti, M., Jackson-Perry, D., Brownlow, C., Fletcher, K., Bendelman, D. & O'Dell, L. 2019. "Doing It Differently: Emancipatory Autism Studies within a Neurodiverse Academic Space." *Disability & Society* 34 (7-8): 1082–1101. doi: 10.1080/09687599.2019.1603102.
- Brugha, T. S., Cooper, S., McManus, S., Purdon, S., Smith, J., Scott, F., ... Tyrer, F. (2012). *Estimating the prevalence of autism spectrum conditions in adults: Extending the 2007 adult psychiatric morbidity survey*. Retrieved from http://www.somesw.co.uk/MyNurChat/archive/LDdownloads/Est_Prev_Autism_Spec_Cond_in_Adults_Report.pdf
- Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L. A., & Hill, E. L. (2018). Autism diagnosis in the United Kingdom: Perspectives of autistic adults, parents and professionals. *Journal of Autism and Developmental Disorders*, 48(11), 3761–3772. doi: 10.1007/s10803-018-3639-1
- Finley, L. 2002. "Outing' the Researcher: The Provenance, Process, and Practice of Reflexivity." *Qualitative Health Research* 12 (4) doi:10.1177/104973202129120052.
- Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., . . . Pellicano, E. (2018). Making the future together: shaping autism research through meaningful participation. *Autism*. doi:10.1177/1362361318786721
- Haraway, Donna. 1988. "Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective." *Feminist Studies* 14 (3): 575–599. doi: 10.2307/3178066.
- Heasman, B., & Gillespie, A. (2019). Neurodivergent intersubjectivity: Distinctive features of how autistic people create shared understanding. *Autism*, 23(4), 910–921.
- Hurley, Elisabeth. (2014). *Ultraviolet Voices: Stories of Women on the Autism Spectrum*. UK: Autism West Midlands.
- Kelly, C., Sharma, S., Jieman, A-T., & Ramon, S. (2022) Sense-making narratives of autistic women diagnosed in adulthood: A systematic review of qualitative research . *Disability & Society*. Doi: 10.1080/09687599.2022.2076582
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442–462. doi:10.1177/1362361315588200
- Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *Journal of the American Academy of Child and Adolescent Psychiatry*, 56(6), 466–474. doi: 10.1016/j.jaac.2017.03.013
- May, T. & Perry, B. (2017). *Reflexivity: The Essential Guide*. London: Sage.
- Milton, D. E. (2012). On the ontological status of autism: the 'double empathy problem'. *Disability & Society*, 27 (6), 883–887. doi:10.1080/09687599.2012.710008
- Milton, D. E. (2017). *A mismatch of salience: explorations of the nature of autism from theory to practice*. London: Pavilion Press.
- Murray, D. (2020). Dimensions of Difference. In: *The Neurodiversity Reader: Exploring Concepts, Lived Experience and Implications for Practice*, edited by D. Milton. UK: Pavilion.
- Williams, D. (1996) *Autism: An Inside-Out Approach*. London: Jessica Kingsley.
- Willig, C. (2013). *Introducing Qualitative Research in Psychology*. UK: McGraw-Hill Education.