

Abstract

Background: Applied Behavioural Analysis (ABA) remains the 'gold standard' for 'positive' autism intervention, with recent research focusing on the pursuit of early intervention at the most initial stage of development (Dennis et al., 2013; Ismail et al., 2017) to entail the strongest possible outcomes for the individual. Despite the perceived success, little of the autistic narrative is conceptualised into practice and outcomes.

Reasoning: Approaches within academia are taking a gradual turn, encompassing the autistic narrative into areas considered in the macro social sense (see Kenny et al, 2016; Cage et al, 2018). One of the more commonly adopted methodologies, ABA has been implemented over more than four decades, yet autistic reflections of this intervention are altogether absent from findings. Given the reportedly dialectic differentials between positive and negative reflections through personal blogs (see Kedar, 2011; Lowery, 2017; "My experiences with ABA", 2017) and ABA-led organisations, paired with a move towards stronger participatory and voice focused research, exploring this lived narrative is, in terms of this research, the next plausible act. Utilising challenges to 'challenging behaviour' and applications of 'Double-Empathy (Milton, 2012), this research looks to the personalised narrative to address discrepancies in outcomes.

Aims and Method: The research aimed to evaluate and disseminate experiential narrative to promote voice in the autistic experiences of ABA in childhood. No specified profile of autism was adopted in order to allow for wider voice participation and develop a narrative centred on those most likely to be perceived as attaining 'benefit' from ABA participation. Reflection of these narratives alongside both empirical literature and practice implications were evaluated and discussed.

Links to questionnaires or details for possible participants to contact were shared through social media and Autism Research based websites. Participants were able to either complete an anonymous questionnaire or contact the researcher to arrange an interview or communicate narratives.

Results: Grounded Theory analysis provided an insight into voice and narrative not yet touched upon within empirical research. Reflections from 13 participants were indicative of a predominantly detrimental impact of ABA (n=10), although some individuals reasoned resolve with certain characteristics being perceived as positive for their own development (n=3). Some emerging themes include reflection on 'removal of autistic self', 'increased vulnerability', 'missed empathic response' and 'autistic led alternatives', with more detail being discussed. Reflections also entail a clear divide between ideology of practice implications, with participants deliberating on the perceived differences between behavioural practice and peer-driven methods.

Discussion: Emergent themes demonstrate a clear antithesis between ABA practices and perceived wellbeing in comparison to experienced quality of life. Participant reflections also highlight significant discourse between empirical conclusions and actualised outcomes; one area in which reflections mirror research follows the recent findings of raised levels of Post-Traumatic Stress Symptoms emanating from ABA experiences (Kupferstein, 2018) through 'Trauma' and 'Mental Health' themes. Through evaluation of lived experiential narratives, the application for practice is also addressed alongside emulation of the autistic voice in implementation of changes to increase both participation in life-intervening applications and progression of self and self-understanding.