Upvote or Downvote ABA for Autism? Content and Support in Reddit Posts

Karen Whisenhunt Saar[a,*], Michael Saar[b], Monica Bellon-Harn[c,d], William Harn[c], Ryan Boyd[e], and Vinaya Manchaiah [d,f,g,h,i]

[a]Department of Speech and Hearing Sciences, Lamar University, Beaumont, Texas, USA;

[b]Mary and John Gray Library, Lamar University, Beaumont, Texas, USA;

[c]Department of Communication Sciences and Disorders, Piedmont University, Demorest, Georgia, USA;

[d]Department of Speech and Hearing, School of Allied Health Sciences, Manipal, Karnataka, India;

[e]Independent, Washington, District of Columbia, USA;

[f]Department of Otolaryngology–Head and Neck Surgery, University of Colorado School of Medicine, Aurora, Colorado, USA;

[g]UCHealth Hearing and Balance, University of Colorado Hospital, Aurora, Colorado, USA;

[h]Virtual Hearing Lab, Collaborative Initiative between University of Colorado School of Medicine and University of Pretoria, Aurora, Colorado, USA;

[i]Department of Speech-Language Pathology and Audiology, University of Pretoria, Pretoria, Gauteng, South Africa

*CONTACT: Karen Whisenhunt Saar. Department of Speech and Hearing Sciences, Lamar University, Beaumont, Texas, USA. Email: kwsaar@lamar.edu

Abstract

Reddit discourse surrounding treatments for autistic individuals is easily accessible. Multiple Reddit threads discuss Applied Behavior Analysis (ABA) as one option. Such content impacts decision-making despite the absence of gatekeeping mechanisms to identify mis-information. Using a cross-sectional design, this study explores perceptions of ABA-based interventions shared on Reddit by exploring posts' content, stance and evidence used to support claims. Posts examined generally lacked support of scientific evidence. Additionally, perspectives on ABA were influenced by personal experiences with the intervention. This data provides insight to support healthcare professionals and families engaged in shared decision-making regarding intervention choices.

Keywords: Applied behavior analysis; authority; autism spectrum disorders; health information literacy; interventions-psychosocial/behavioral; misinformation; social media

Introduction

The use of social media as a platform for health information communication has gained attention in recent years. While some families of Autistic children prefer to seek health information from established, local resources, others turn to social media for support and information (Caton, Koivunen, and Allison 2019; Cole et al. 2017; Gibson, Kaplan, and Vardell 2017). These platforms allow users to discourse on health-related information and advocacy but may contribute to the spread of misinformation (Bellon-Harn, Ni, and Manchaiah 2020; Chipidza et al. 2022; Tasnim, Hossain, and Mazumder 2020; Wang, Shi, and Kong 2021). Platforms like Reddit are particularly popular owing to their accessibility and user-generated content yet remain a relatively unexplored site of empirical research in comparison to larger entities such as Twitter and Facebook (Yeung et al. 2022). Additionally, a recent review of existing empirical studies utilizing Reddit data, warn that much of the knowledge generated about Reddit content is gained via computational textual analysis and encourage further contextualization of this data (Proferes et al. 2021). There is a growing body of research exploring Reddit as a site for the discussion of topics related to autism spectrum disorder (ASD) and its treatment options. These discussions often occur within various "subreddits," targeted forums, covering different aspects of autism. Among those empirically researching Reddit content specific to ADS, Bellon-Harn, Boyd, and Manchaiah examined the representation of applied behavior analysis (ABA) intervention in Reddit discourse using topic modeling (2022). The current study builds on this research by examining ABA discourse on Reddit utilizing inductive manual coding of contextualized thread content.

Frequently referenced as the gold standard intervention for ASD (Wilkenfeld and McCarthy 2020), applied behavior analysis (ABA) is an intervention practice founded in the science and philosophy of behaviorism and behavioral analysis (Lovaas 1987; Leaf et al. 2021). Behavior analysis, as a science, studies how to manipulate environmental contexts and stimuli to increase probability of socially desired behaviors and decrease probability of socially undesired behaviors. The application of this science in ABA intervention aims to identify and change behavior targets in a replicable manner by systematically utilizing positive or negative reinforcement response stimuli (Cooper, Heron, and Heward 2020). While ABA is a field of practice with delineated educational tracts such as a board-certified behavior analyst (BCBA), ABA methods may also be adopted by other professionals such as teachers and speech-language pathologists. Notwithstanding controversy about ethical concerns regarding intervention practices, foundational theories, and potential traumatic effects of ABA intervention (Sandoval-Norton, Shkedy, and Shkedy 2019; Wilkenfeld and McCarthy 2020), ABA receives support from practitioners in the ABA field, other healthcare disciplines, and from families of individuals receiving services (Foxx 2008; Grindle et al. 2009; Griffith, Fletcher, and Hastings 2012; Hastings and Symes 2002; Makrygianni et al. 2018). Despite ABA's prevalence, there has been significant criticism of the treatment. Individuals with an autism spectrum disorder (ASD) diagnosis, parents, caregivers, and professionals express varied perceptions of ABA including concerns related to impacts and implementation of therapy, as well as the training and expertise of ABA professionals (Callahan et al. 2019; Dillenburger et al. 2012; Kupferstein 2019). Other concerns include accessibility issues related to ABA (i.e., availability, cost) and access to non-ABA alternative interventions (Tschida et al. 2021). As some families utilize online

information to guide healthcare decision-making, these concerns point to a need to better understand how ABA is portrayed in Reddit threads.

Understanding the nature and content of online discussion about ABA may help healthcare professionals engage in family-centered practice and shared decision making. Shared decision-making entails sharing the best available evidence between professionals and families to support informed choices. For this to occur, families need both access to cultural and contextually appropriate evidence-based information and guidance on their options (Elwyn et al. 2010) in accordance with heath literacy best practice. This necessitates the ability to identify credible information which can be challenging in the social media environment.

Information uptake in social media

Role of authority

Anyone can engage in conversations on Reddit; however, the absence of a gatekeeping function means no mechanism is in place to mitigate the spread of misinformation and bias. In traditional settings this gatekeeping is done through established sources of authority such as medical professionals and scientific researchers. Yet, these are not necessarily the primary voices represented in social media discourse. Information, as well as the authority of those who create it, exists within a historical and social context which influences considerations regarding its accuracy, reliability, and application (Kaplan 2018; Saunders and Budd 2020). This is noticeable in the increasingly large numbers of adults who utilize social networks to access news and information (Shearer and Mitchell 2021). Each Reddit poster comes to the thread with a perspective cultivated through a combination of unique experiences and social connections.

Information creation and interpretation is contextual. Experiences and social ties that connect us to our communities through education, diagnostic label, or profession, serve to shape our views of the world, as well as how we encounter and understand new information (Berger and Luckmann 1966; Critten and Stanfield 2016). Social media platforms provide equal consideration for information shared by all users, yielding a space in which authority can be negotiated differently. Informal social media discourse surrounding ABA is occurring with little knowledge about the constellation of users engaged in these exchanges. Consumers turning to Reddit may encounter novel perspectives unavailable via a medical provider. Such online information can negatively impact parental trust in physician credibility (Pham et al. 2019). Social media sites such as Reddit provide easy access for information sharing. Posts are publicly available for anyone to read and those who wish to contribute to the discussion need only an email address to create an account. with existing content by actively participating in thread discussion or simply reading discussion posts created by others.

Although Reddit has many elements common with other popular social media sites (e.g., sharing and creating information), it also has significant differences. For one, Reddit is more anonymous than Facebook or Twitter. Reddit's content is accessible to anyone with or

without an account. While an account is required to post information, accounts are not typically tied to any personally identifiable information. Additionally, optional "throwaway accounts'' allow individuals to post on topics they may not wish associated with their primary account. Proposed identities, backgrounds, and informational context cannot be verified. Reddit users with an account can subscribe to one more subreddits, groups gathered around a particular issue, to allow focused discussion and information sharing on that topic. While the felicity of joining subreddits can allow for greater information sharing and foster a supportive community, it conversely runs the risk of turning into an echo chamber; where outlier or dissenting viewpoints are not able to surface. Consequently, information shared and obtained via social media platforms is not without risk of misinformation and bias.

Misinformation and bias

Misinformation has seen increasing notoriety in recent years, both in popular media and scholarly circles (Allcott and Gentzkow 2017; Kakutani 2018; O'Connor and Weatherall 2019). It is a persistent problem as misinformation tends to be believed by readers, can quickly and easily reach mass audiences, and is difficult to counteract (Southwell and Thorson 2015). Research suggests social media usage can exacerbate the impact biases hold in the decision-making process, ranging from confirmation biases to inflating one's own sense of expertise (Nickerson 1998; Nisbet, Cooper, and Garrett 2015; Kruger and Dunning 1999; Fisher, Goddu, and Keil 2015). Additionally, the determination of a message's trustworthiness is often filtered through the opinions of social peers regardless of those individuals' expertise or subject knowledge (Lewandowsky et al. 2012; Mahmoodi et al. 2015). The ability to self-select one's social information circle, a common feature in social media platforms, compounds this problem. Insulating oneself within these "echo chambers" reinforces assumptions and silences dissenting information. Participation in such curated social communities may result in a lack of diversity and increased levels of polarization (Nikolov et al. 2015; Bright 2018; Del Vicario 2016). Difficulty in isolating reliable information is further amplified through various algorithms that influence how resources and results appear in one's news feed. Lack of transparency and clarity linked to algorithms operates as barriers to determining the quality of information being presented (O'Neil 2016; Ciampaglia et al. 2018; Kaplan 2018). This is worsened by how rapidity and repetition factor into misinformation acceptance (Friggeri et al. 2014; Vosoughi, Roy, and Aral 2018). Additionally, users on Reddit may work to influence others to align with their perspective, often by playing on emotions (Li and Suh 2015; Shu et al. 2017). Users also influence others by establishing common ground (i.e., harmonizing) which may demonstrate like-mindedness and trigger a reader's convergence into a given perspective. Online discourse may provide a context that more successfully influences others than offline discourse, contributes to misinformation, and impacts healthcare communication (Procter 2021).

Study aim

Reddit threads serve different functions for different stakeholders associated with autism, which can influence the content and purpose of information shared (Bellon-Harn, Ni, and Manchaiah 2020). This manuscript seeks to contribute to information regarding perceptions

of ABA-based intervention as shared on the social media platform, Reddit. The specific aims are to: (a) identify the content of posts, (b) examine the relationships between content and users view toward ABA (i.e., pro- versus anti-ABA posts); (d) identify whether and how support is made for claims made in the posts.

Method

Study design and ethical considerations

The study used a cross-sectional analysis of data generated from reddit.com. Conversations about ABA in relation to autism were extracted from Reddit. Ethical approval is not required as the data was anonymous and no personally identifiable information was included (Eysenbach and Till 2001). Consequently, this study was deemed exempt from review by the Lamar University as information was publicly available online.

Data extraction

The dataset for this study is part of a larger study, currently under review. The dataset consists of original posts (i.e., conversation-initiating submissions) and associated comments (i.e., replies to original posts) from several topical focused subreddits. Discussions about ABA for autism were extracted via the Reddit application programming interface (API) using a custom-built script. This Reddit API is publicly accessible and allows researchers to acquire language data directly from the platform without using the typical web interface.

To identify the relevant threads containing posts about ABA in relation to ASD, a search was performed in Reddit using key words such as "Applied Behavior Analysis," "ABA Therapy," "Autism," or "Autism Spectrum Disorder" and a list of threads were compiled. The search was sorted by relevance utilizing the "from all time" filter. Threads that had a focus on ABA were included. The data was extracted from 19 subreddit threads, although much of the data was generated from a few subreddits, including r/autism (62%), r/aspergers (13%), r/BehaviorAnalysis (6%), r/ABA (3.5%), r/Parenting (3%), r/unpopularopinion (2.7%), and r/IAmA (2.3%).

The approach to data extraction was to collect the entire thread history. Where possible, all original post-level information was retained. If user-level information was included, that information was removed from the post data. Thread entries were separated from the context of the thread to analyze opening posts and reply comments separately. For the remainder of this paper, both types of thread entries will be generically referred to as a post. Reddit does not collect thorough demographic data on the site's users; thus, characteristics of the sample could not be described. The data posted through March 2020 were extracted chronologically.

A total of 2,432 posts were extracted. 112 posts that were not relevant to ABA were excluded. Lack of relevance was determined by posts without much information (fewer than 5 words, such as "Thanks.") All posts from the original dataset were coded according to the

view toward ABA. The third author and a graduate student manually coded the initial 100 posts according to whether the post included support of ABA (i.e., pro-ABA); did not include support (anti-ABA); were seeking information about ABA (i.e., neutral/curious); or were not directly related to ABA (i.e., unclassified). Unclassified posts did not relate to ABA even if they were related to some aspect of autism causes, characteristics, or treatment. Upon review and discussion by the two coders, the graduate student completed coding the posts. Following each 100 posts, the sample was sent to the third author for review and to resolve queries. Of the main, larger dataset, only the posts identified as pro- or anti-ABI were analyzed for this study. Of the 2,320 posts, 462 (47.9%) posts were identified as pro-ABA and 502 (52.1%) as anti-ABA. Consequently, 964 posts were included in this study.

Data analysis

Once the dataset was comprised, preliminary manual coding of 100 posts provided initial codes. An initial in vivo coding explored perspectives expressed by Reddit users in posts. A second cycle of focused coding established conceptual similarities and eventual code categories from the content of the posts (Saldaña, 2016). Upon cyclical review and discussion by the first four authors, content codes were developed. Codes were generated to explore posts' content, and evident support for claims. Upon review and discussion among by the first four authors, codes were developed for each aspect of examination. Following development of the codes, two teams from the initial four authors continued to code subsequent posts within each category and discuss those that needed deliberation and consensus. Per Chew and Eysenbach (2010) where multiple qualifiers were present within a post, all applicable qualifiers were used.

Posts were also coded according to the personal identification of their status. The third author and a graduate student coded posts according to the personal identification of status in the post as an Autistic person, a parent of an Autistic individual, or a professional. In order to be coded, the post explicitly stated their status (e.g., as an autistic adult). If it did not, it was coded as other.

Manual codes were converted into multiple binary variables (i.e., coded as 0 if information relevant was not present in post or coded as 1 if post included information relevant to a code).

Statistical analysis

SPSS software was used for statistical analyses. Descriptive statistics were used to describe user categories, frequency of content categories, purpose categories, and support categories. Chi-square was performed to examine the difference in each group (pro-ABA and anti-ABA) on content, purpose, and support variables. A p-value of .05 was used for statistical significance interpretations.

Kappa was performed to examine the inter-rater reliability for coding on a random sample of 20% of the posts. Kappa for content coding ranged between .73 and .99, for communicative purpose between .83 and .92, and for claims of support between .74 and .97. All values suggest good reliability.

Results

All posts from the original dataset were coded according to the view toward ABA. Posts were either coded as Pro ABA, Anti ABA, or other if stance toward the intervention was not overtly apparent within the post. Of the main, larger dataset, only the posts identified as pro- or anti-ABI were analyzed for this study. Of the 2,320 posts, 462 (47.9%) posts were identified as pro-ABA and 502 (52.1%) as anti-ABA. Consequently, 964 posts were analyzed for this study across each of the areas of focus: post content and inclusion of support for claims.

User categories

Of the 964 posts included in this study, 209 (21.7%) were identified as posted by individuals who self-identified as a parent of a child with ASD, 200 (20.7%) as a professional, and 120 (12.4%) as a person with ASD. A majority were identified as "other" (i.e., 435 posts, 45.1%). Posts by parents and professionals were predominately pro-ABA, while a majority of posts by persons with ASD or "other" were anti-ABA. User categories are listed in Table 1.

Content

The largest category of posts included content related to abuse or misuse of ABA (i.e., 33.5%), followed closely by posts describing benefits of ABA (31.8%). See Table 2. Posts describing ABA as a misunderstood or misrepresented field (21.5%), posts calling for neurodiversity (18.7%), posts describing trauma associated with ABA (12.2%), and posts describing professional and supervisory relationships (10.3%) occurred with higher frequency than posts referencing limited, valid, or neutral scientific foundations for ABA (7.2%, 8.1%, and 6.7% respectively), access to ABA (i.e., 7.6%), and relationships between professionals and parents (7.9%). Less frequent posts included posts explicitly recommending ABA services (2.2%) and discussions relating to high- versus low-functioning presentation of ASD (2.9%). As evidenced in Table 2 below, there was a relationship between users view toward ABA and the following content categories: abuse/misuse, limited scientific foundations, valid scientific foundations, associated trauma, call for neurodiversity with anti-ABA posts, access to ABA services, benefits of ABA, relationships between parents and professionals, relationships between professionals and supervisors, and ABA as a misunderstood field. Table S1 in the Supplemental Material provides example posts categorized according to the code book for content posts.

Support for claims

Overt claims were present in 657 (68%) posts as noted in Table 3. Of these, the majority did not reference support for claims (30.3%) followed slightly by anecdotal support for claims (26.7%). The fewest number of posts referenced external research (7.2%) or cited personal research (4%). Table S2 in the Supplemental Material presents post examples categorized according to the support for claims code book.

Table 1. User categories.

Identify	Total posts	Pro-ABA posts	Anti-ABA posts
Parent	209 (21.7%)	135	74
Person with ASD	120 (12.4%)	25	95
Professional	200 (20.7%)	143	57
Unknown	435 (45.1)	159	276
		462 (47.9%)	502 (52.1%)

Table 2. Content posts.

Category	Example (Additional examples in Table S1)	Post N (%)	Pro N	Anti N	Chi square, p-value	Kappa
Abuse/misuse: This refers to posts that include reference to violated autonomy (thoughts, privacy), abuse (physical or emotional), and coercion (physical and verbal).	"With sensory issues, I am not slightly uncomfortable, I am in pain because I can't tolerate an environment. Forcing me to stay until I meet some esoteric neurotypical bullshit notion of normal behavior is torture."	323 (33.5%)	31	292	285, <.001	.73
Scientific foundations: Lack: This refers to posts that describe ABA as lacking research support.	"There is no evidence that ABA creates any positive outcomes when the child becomes an adult..."	69 (7.2%)	8	61	39, <.001	.85
Scientific foundations: Valid: This refers to posts that describe ABA as having a scientific foundation and evidence base.	"ABA is without a doubt, the most evidence based treatment in terms of decreasing behavior and increasing skills acquisition. There is nothing even close."	78 (8.1%)	69	9	55, <.001	.95
Scientific Foundations: Neutral: This includes posts that emphasize the necessity of a scientific evidence base or discussion around existing scientific evidence. Yet these posts did not indicate a clear stance on whether there was a valid or lacking evidence base for ABA.	"I appreciate your input and I was not aware of that research."	65 (6.7%)	35	30	.95, .2	.85
Accessibility to services: This includes posts that references the cost of insurance, third-party payor, or finding a center and/or trained therapists.	"Due to my insurance specifically not covering therapy related to ASD, I had to spend months getting him on state insurance, and then get him ABA..."	73 (7.6%)	47	26	8.5, .003	.81
Potential or realized benefits of ABA: This includes references to potential or observed positive impacts of ABA.	"In short, we are doing all we can to help my son with his basic needs and communication to us, as well as preventing some more dangerous behaviours."	307 (31.8%)	276	31	317, <.001	.93
Associated trauma: This includes reference to ABA as stigmatizing practice (leads to bullying, teasing), or to ABA participation having led to stress, suicidal thoughts, social anxiety, and trauma in later life.	"I salvaged something from ABA, but I don't even know if I can find a way out of the shame that a life time of trying to pass left me with."	118 (12.2%)	11	107	80, <.001	.87
Stance on neurodiversity: This includes references related to a call for neurodiversity, descriptions of separate social markers based on diagnostic labels, and a call for listening to the voice of individuals with autism.	"I feel like I'm doing best for my child by trying to maintain his humanity, and not "train" the autism out of him."	180 (18.7%)	42	138	54, <.001	.86
Low/high functioning: This includes references that explore claims that there are divisions between people with varying presentations of autism in their response to ABA.	"I know for a fact a few people who commented on the post are considered "low" functioning by diagnosis. Allow me to make a generalization though. The vast majority of autistics, both "high" and "low" functioning, hate ABA."	28 (2.9%)	13	15	.03, 0.5	.99
Professional/parent Relationship: These posts include referenced to stressors and relationships from either direction.	"Why don't we stand up to parents in this field? Would surgeons let patients control their own surgery? Why do we give the parents so much power to control what we're doing?"	76 (7.9%)	49	27	8.9, .002	.89
Professional connections: These posts include references to professional connections to the field, relationships and dynamics between BCBA and BCaBA, and motivations for joining field.	"Current RBT of 3 years, Same boat here. Want to move up in the world, but I am not getting stuck in the ABA box by doing my masters in it."	99 (10.3%)	64	35	12.2, <.001	.83
Recommended: These posts include specific references to provider recommendations and referrals to ABA services.	"I do know that his primary doctor and the doctor who assessed him all say ABA is the treatment. Period. They have been clear that ABA is what you do."	21 (2.2%)	14	7	2.9, .06	.79
Misunderstood and misrepresented field: These posts include descriptions of ABA as a practice that has changed over time, as a misapplication of procedures by a few poor therapists, as a complex intervention not well-understood by outsiders.	"Abusive ABA is pretty much gone and I'm sure you won't have any problems finding someone who can work with your child in a way that suits you."	207 (21.5%)	165	42	106, <.001	.78

Table 3. Support for claims.

Category	Example (Additional examples in Table S2)	Post *N* (%)	Kappa
None: A claim is made but no support is provided for the claim	"Also, it might be interesting to note that electroshock is still widely used and has proven to be effective for several conditions."	292 (30.3%)	.79
Personal/anecdotal: Support is provided for a claim is either anecdotal evidence or a personal anecdote	"My friend went to ABA and it totally ruined her trust in telling adults how she feels."	257 (26.7%)	.97
External expertise (mention/citation): Support refers to research conducted by others in the field. This may include a citation or a general reference to a study or expert.	"ABA and some other therapies aims to change him, which is good **to an extent** but when done intensively can do more harm than good, an article from an autism advocate on ABA and it's origins is [here](https://autismwomensnetwork.org/my-thoughts-on-aba/)"	69 (7.2%)	.75
Own research (activities/expertise): Support refers to research conducted by the poster or their own status as an expert in the field	"Yes, I do have data. I have 8 years and hundreds of clients to provide as data."	39 (4%)	.74

Discussion

This study explored Reddit threads to understand the nature and content of discussions surrounding ABA intervention for autism. Researchers sought to identify who posts within the platform and how participants used the platform to discuss ABA-based intervention. Specifically, researchers examined what content is shared in these posts and by whom, with attention paid also to and relationships between content and overtly pro- versus anti-ABA posts. These findings were further analyzed through an exploration of whether support for claims was included and, if so, that nature of that support. The content of discourse indicates strong differences in attitudes toward this intervention among users. The overwhelming lack of support for these attitudes suggests posters are relying on anecdotal or personal evidence to shape their views. Such inconsistencies may impact perceptions of the practice and leave those seeking answers regarding ABA with more questions regarding ABA-based intervention. Patterns and trends noted in the data provide information regarding current conceptions and concerns about ABA and may help healthcare professionals in discussions with families. This information provides healthcare professionals with exposure to a variety of voices with opposing views on the impact of ABA services. Families may not bring up their exposure to this online discourse to a provider. Thus, provider awareness can guide them to identify credible sources from all perspectives to bring to supporting informed, balanced, and client-centered decision making.

Users analysis

Based on this sample, almost half of users engaged kept their identities anonymous. As noted, anyone can engage in conversations and express perspectives with no established authority. Additionally, "throwaway accounts" may have allowed individuals to post on topics in an effort to charge the conversation in a particular manner. This may shape the perspectives of other users and propagate misinformation and bias (Critten and Stanfield 2016). In turn, this may impact decisions related to ABA as well as interactions with professionals and other sources of authority (Cork and Grant 2016). Of the posts in which identity was shared, nearly 80% of posts by individuals stating they are living with an ASD diagnosis were anti-ABA, whereas individuals self-identifying as parents and professionals provided a higher number of pro-ABA posts. This suggests that the perspective of the individuals targeted and being treated via ABA differs from the perspective of their parents and of those providing the intervention services. This is consistent with literature stating that ABA receives support from practitioners and families, but not from individuals with ASD (e.g., Makrygianni et al. 2018). Although this data is not a comprehensive representation of all information and opinion on ABA-based intervention, this sample reinforces previous work that demonstrates ABA-based intervention is steeped in conflicting conceptions and perspectives.

Content analysis

As discussed in the user analysis section, stances expressed in posts indicated that the perspective of the individuals targeted and being treated via ABA differs from the perspective of their parents and of those providing the intervention services. Anti-ABA posts were more highly associated with misuse and trauma. On the other hand, pro-ABA posts overwhelmingly related to treatment outcomes.

Posts consisting of content other than misuse or benefits of ABA occurred to a much lesser degree but are nonetheless notable. Posts that claimed ABA is a misunderstood practice or field were mainly from posts identified as pro-ABA. These posts suggest trust in professionals is inconsistent and that practitioners of ABA may feel their practice is misunderstood. As noted, parents are concerned about adequate training of ABA professionals (Callahan et al. 2019) and the current data indicates that this concern is being expressed on social media. Concerns noted in posts also included references to neurodiversity and inclusion. Referencing a perceived lack of representation of autistic perspectives in scientific literature, one poster exclaims,

> …the basic fact of the matter is that autistic people are massively underrepresented in the medical community, our voices are ignored, and we've never been given a platform to mount a defence… So its incredibly insulting for you to suggest that your abundance of medical literature is somehow a defence. Its not. Its indicative of the ableist situation we find ourselves in.

Such posts indicate that this population may find that Reddit provides a platform to share concerns related to the call for inclusion.

The total number of comments about lack, validity, or neutrality of scientific foundations of ABA were equivalent. However, comments about scientific evidence varied between pro- and anti-ABA posts. Anti-ABA posts discredited any references to ABA or discussed the lack of credibility of the practice. Alternatively, a majority of posts claiming that ABA is supported by evidence-based practice were classified as pro-ABA. Claims of the scientific evidence base demonstrate that some pro-ABA posters lean more heavily on research over the negative claims of individuals with ASD. Such comments indicate that lived experiences are not perceived to be an acceptable source of evidence and that the long-term psychological impact of ABA practices are considered by some to be of low value.

The differences in the content of posts by pro- versus anti-ABA Reddit posters cautions that individuals with different experiences with and roles associated with ABA draw on very different information to form their opinion. Practitioners need to understand that Reddit discourse does not reflect a direct dialogue between opposing opinions and there are no arbiters of authority or quality in place to guide the nature and content of information-sharing. Consequently, the healthcare professional may be able to bridge the divide during direct conversations with families. The content of the discourse indicates that individuals on either side of the issue do not hear each other and value different types of information in decision making. Practitioners making recommendations for services may best serve their clients by being open and honest about the overall risks and benefits, acknowledging not only claims of benefits from medical providers, but also warnings from those with a lived

experience as recipient of ABA care. In doing so, providers can be balanced and deliberate in directing clients to valid sources on both sides of the controversy.

Support for claims

Of the 964 posts, 307 posts made no claims. Of the 657 (68%) posts that did make an overt claim, the largest set of posts provided no support for their claims. The next-largest set provided only personal/anecdotal evidence as support. Only 7% of claim posts included reference to external research of any kind. This small number is despite a wide definition of external research to include a of peer-reviewed research as well as any general reference to a research study or external expert opinion. Individuals who identify as experts in field were largely absent in this conversation, based on the available information from post content. Thus, the majority (almost all) of posts that included some sort of claim did not provide anything beyond anecdotal support for their post or stance. This lack of evidence, while not surprising in an informal medium like Reddit, is a cause for concern especially as research indicates online searchers often conflate access to information with the perception of obtained knowledge (Fisher et al., 2015).

Implications and conclusions

It is critical for healthcare professionals to know the nature of information being shared online to support families in evidence-based decision making. This need is heightened when considering treatments that have garnered excitement and controversy. Based on this data, perceptions on both sides of the issues are impacted, in many cases, by personal experience. Some posters state, "I was trained like a dog." while others respond that the intervention is misunderstood, that over time ABA therapies have become "more appropriate" and that "Abusive ABA is pretty much gone" or even that "It was a VERY need action…I would not have been able to go to a school without disability accommodations without ABA services" (all quotes found in Supplementary Material, Table S1). However, the types of experience do not hold equal weight in guiding decisions made for children with ASD. This data provides insight for healthcare professionals to engage in family-centered practice and shared decision making.

Posts surrounding personal experience of abuse and lasting trauma associated with ABA such as, including "Being told not to react with aversion to certain stimuli, like physical contact, eye contact etc., is the same as being told to ignore pain and distress", are of concern. Some posters indicate feeling provoked or devalued, recognizing that they have been trained to undervalue their authenticity to pass as neurotypical. One poster wrote that, despite having enjoyed ABA as a child, there was lasting trauma from the way success was measured:

> ABA also is so data-driven from a quantitative sense that it fails to account for qualitative data- things that science CAN examine via research, but with data types that do not match 'effectiveness' based research. There is very little understanding of what happens to those kids as they become adults after ABA. A LOT of them have mental health diagnoses now, and things that came up in ABA are now coming up in therapy. There is a lot of trauma even for the people who had 'fun' ABA. Including me.

As acknowledged by some posters, targeting neurotypical mannerisms as success in such interventions may be ignoring neurodiverse perspectives and needs:

> …the exclusive focus on learning to "pass" as neurotypical set me up for a lifetime of shame and isolation. When you pass, you make every human interaction a lie. You imbibe the lie that who you are is not acceptable… All the while you are dying inside because you want someone to know who you are. You need it - autistics are human and need human contact and love like everyone else. And yet, we are trained to make ourselves invisible.

Such comments challenge the definition of success through the lens of one population over the population served. Certainly, these issues must not only be considered by professionals initiating conversations about treatment options, but also by researchers in how they define and track "success" in data designed to explore success of ABA treatment.

Clearly Reddit posts lack scientific evidence and include primarily personal anecdotes. Healthcare professionals may wish to be prepared with evidence-based information that is presented in a manner that is accessible to the general population and follows health literacy best practices. Knowing that parents may be encountering information that lacks credibility, practitioners can come to care planning sessions prepared to provide clarity and guidance. This could include clearly explaining ABA alongside alternative treatment options, which is a reported need of families (Tschida et al. 2021). Additionally, the professional may wish to explain expected outcomes and potential benefits of ABA concurrent with other interventions that may impact other ASD symptoms.

Limitations and future directions

Views and levels of professional support for ABA vary in different regions of the world. (Liao et al. 2018). However, this study did not compare posts relative to different geographic locations. It is important to note that this data is not representative of the general population, which is likely the case for most social media studies. For example, Reddit users have been found to be predominantly male (67%) and White (54%) (Walker and Matsa 2021). Valuable insights were gained by interpreting the content of each individual post extracted. However, it is possible that viewing posts in isolation obscured additional information that an analysis of a contextualized online discourse could provide. Additionally, we do not know the number of users represented, which may limit our understanding of the reach of the population. This is compounded by the number of users that are anonymous. Future studies should focus on performing more in-depth analysis of connected discourse to examine the specific narratives used and the tensions among posts from these groups.

Notes on contributors

Karen Whisenhunt Saar

Karen Whisenhunt Saar, PhD (kwsaar@lamar.edu), is an Assistant Professor in the Department of Speech and Hearing Sciences, Lamar University, Beaumont, Texas, USA.

Michael Saar

Michael Saar, MLS (mksaar@lamar.edu), is an Associate Professor and interim Dean, of the Mary and John Gray Library, Lamar University, Beaumont, Texas, USA.

Monica Bellon-Harn

Monica Bellon-Harn, PhD (mharn@piedmont.edu), is Professor and Director of the Department of Communication Sciences and Disorders, Piedmont University, Demorest, Georgia, USA.

William Harn

William Harn, PhD (wharn@piedmont.edu), is in the Department of Communication Sciences and Disorders, Piedmont University, USA.

Ryan Boyd

Ryan Boyd, PhD (ryan@ryanboyd.io), is an independent researcher, in Washington, DC, USA.

Vinaya Manchaiah

Vinaya Manchaiah, PhD (vinaya.manchaiah@cuanschutz.edu), is Professor & Director of Audiology, Department of Otolaryngology–Head and Neck Surgery, Anschutz Medical Campus, University of Colorado, Aurora, Colorado, USA.

References

Allcott, H., and M. Gentzkow. 2017. Social media and fake news in the 2016 election. *Journal of Economic Perspectives* 31, no. 2: 211–236. doi:10.1257/jep.31.2.211

Bellon-Harn, M.L., R.L. Boyd, and V. Manchaiah. 2021. Applied behavior analysis as treatment for autism spectrum disorder: Topic modeling and linguistic analysis of Reddit posts. *Frontiers in Rehabilitation Sciences* 2: 682533. doi:10.3389/fresc.2021.682533.

Bellon-Harn, M.L., J. Ni, and V. Manchaiah. 2020. Twitter usage about autism spectrum disorder. *Autism: The International Journal of Research and Practice* 24, no. 7: 1805–1816. doi:10.1177/1362361320923173.

Berger, P. L., and T. Luckmann. 1966. *The social construction of reality: A treatise in the sociology of knowledge*. New York: Anchor Books.

Bright, J. 2018. Explaining the emergence of political fragmentation on social media: The role of ideology and extremism. *Journal of Computer-Mediated Communication* 23, no. 1: 17–33. doi:10.1093/jcmc/zmx002.

Callahan, K., R.M. Foxx, A. Swierczynski, X. Aerts, S. Mehta, M.-E. McComb, S.M. Nichols, G. Segal, A. Donald, and R. Sharma.2019. Behavioral artistry: Examining the relationship between the interpersonal skills and effective practice repertoires of applied behavior analysis practitioners. Journal of Autism and Developmental Disorders49, no. 9:3557–3570. doi:10.1007/s10803-019-04082-1.

Caton, S., E.-R. Koivunen, and C. Allison. 2019. Internet use for family carers of people with intellectual disabilities: A literature review and thematic synthesis. *Journal of Intellectual Disabilities* 23, no. 3: 446–468. doi:10.1177/1744629519874214.

Chew, C., and G. Eysenbach. 2010. Pandemics in the age of Twitter: Content analysis of tweets during the 2009 H1n1 outbreak. *PLoS ONE.*5, no. 11: e14118. doi:10.1371/journal.pone.0014118.

Chipidza, W., C. Krewson, N. Gatto, E. Akbaripourdibazar, and T. Gwanzura.2022. Ideological variation in preferred content and source credibility on Reddit during the COVID-19 pandemic. Big Data & Society9, no. 1: 20539517221076486. doi:10.1177/20539517221076486.

Ciampaglia, G.L., A. Nematzadeh, F. Menczer, and A. Flammini. 2018. How algorithmic popularity bias hinders or promotes quality. *Scientific Reports* 8, no. 1: 15951. doi:10.1038/s41598-018-34203-2.

Cole, L., Y. Kharwa, N. Khumalo, J.S. Reinke, and S.B.S. Karrim. 2017. Caregivers of school-aged children with autism: Social media as a source of support. *Journal of Child and Family Studies* 26, no. 12: 3464–3475. doi:10.1007/s10826-017-0855-9.

Cooper, J., T. Heron, and W. Heward. 2020. Applied Behavior Analysis. 3rd ed. London: Pearson.

Cork, N., and P. Grant. 2016. Blurred lines: The general medical council guidance on doctors and social media. *Clinical Medicine* 16, no. 3: 219–222. doi:10.7861/clinmedicine.16-3-219.

Critten, J., and A. G. Stanfield. 2016. Social constructivism and critical information literacy. In *Critical library pedagogy handbook volume 1: Essays and workbook activities*, ed. N. Pagowsky and K. McElroy, Vol. 1, 85–92. Chicago: Association of College and Research Libraries.

Del Vicario, M., G. Vivaldo, A. Bessi, F. Zollo, A. Scala, G. Caldarelli, and W. Quattrociocchi.2016. Echo chambers: Emotional contagion and group polarization on Facebook. Scientific Reports6, no. 1: 37825. doi:10.1038/srep37825.

Dillenburger, K., M. Keenan, A. Doherty, T. Byrne, and S. Gallagher. 2012. ABA-based programs for children diagnosed with autism spectrum disorder: Parental and professional experiences at school and at home. *Child & Family Behavior Therapy* 34, no. 2: 111–129. doi:10.1080/07317107.2012.684645.

Elwyn, G., D. Frosch, A.E. Volandes, A. Edwards, and V.M. Montori. 2010. Investing in deliberation: A definition and classification of decision support interventions for people facing difficult health decisions. *Medical Decision Making* 30, no. 6: 701–711. doi:10.1177/0272989X10386231.

Eysenbach, G., and J.E. Till. 2001. Ethical issues in qualitative research on internet communities. *BMJ (Clinical Research ed.)* 323, no. 7321: 1103–1105. doi:10.1136/bmj.323.7321.1103.

Fisher, M., M.K. Goddu, and F.C. Keil. 2015. Searching for explanations: How the internet inflates estimates of internal knowledge. *Journal of Experimental Psychology: General* 144, no. 3: 674–687. doi:10.1037/xge0000070.

Foxx, R.M. 2008. Applied behavior analysis treatment of autism: The state of the art. *Child and Adolescent Psychiatric Clinics of North America* 17, no. 4: 821–834. doi:10.1016/j.chc.2008.06.007.

Friggeri, A., L. Adamic, D. Eckles, and J. Cheng. 2014. Rumor cascades. Proceedings of the International AAAI Conference on Web and Social Media 8, No. 1 (May 16). https://ojs.aaai.org/index.php/ICWSM/article/view/14559.

Gibson, A.N., S. Kaplan, and E. Vardell. 2017. A survey of information source preferences of parents of individuals with autism spectrum disorder. *Journal of Autism and Developmental Disorders* 47, no. 7J: 2189–2204. doi:10.1007/s10803-017-3127-z.

Griffith, G.M., R. Fletcher, and R.P. Hastings. 2012. A national UK census of applied behavior analysis school provision for children with autism. *Research in Autism Spectrum Disorders* 6, no. 2: 798–805. doi:10.1016/j.rasd.2011.10.014.

Grindle, C.F., H. Kovshoff, R.P. Hastings, and B. Remington. 2009. Parents' experiences of home-based applied behavior analysis programs for young children with autism. *Journal of Autism and Developmental Disorders* 39, no. 1: 42–56. doi:10.1007/s10803-008-0597-z.

Hastings, R.P, and M.D. Symes. 2002. Early intensive behavioral intervention for children with autism: Parental therapeutic self-efficacy. *Research in Developmental Disabilities* 23, no. 5: 332–341. doi:10.1016/S0891-4222(02)00137-3.

Kakutani, M. 2018. *The death of truth*. New York: Tim Duggan Books.

Kaplan, S. 2018. Encouraging information search to counteract misinformation: Providing "balanced" information about vaccines. In *Misinformation and mass audiences*, ed. B.G. Southwell, E.A. Thorson, and L. Sheble, 274–288. Austin: University of Texas Press.

Kruger, J., and D. Dunning. 1999. Unskilled and unaware of it: How difficulties in recognizing one's own incompetence lead to inflated self-assessments. *Journal of Personality and Social Psychology* 77, no. 6: 1121–1134. doi:10.1037/0022-3514.77.6.1121.

Kupferstein, H. 2019. Why caregivers discontinue applied behavior analysis (ABA) and choose communication-based autism interventions. *Advances in Autism* 6, no. 1: 72–80. doi:10.1108/AIA-02-2019-0004.

Leaf, J.B., J.H. Cihon, J.L. Ferguson, C.M. Milne, R. Leaf, and J. McEachin. 2021. Advances in our understanding of behavior intervention: 1980 to 2020 for individuals diagnosed with

autism spectrum disorder. *Journal of Autism and Developmental Disorders* 51, no. 12: 4395–4410. doi:10.1007/s10803-020-04481-9.

Lewandowsky, S., U.K.H. Ecker, C.M. Seifert, N. Schwarz, and J. Cook. 2012. Misinformation and its correction: continued influence and successful debiasing. *Psychological Science in the Public Interest* 13, no. 3: 106–131. doi:10.1177/1529100612451018.

Li, R., and A. Suh. 2015. Factors influencing information credibility on social media platforms: evidence from Facebook pages. *Procedia Computer Science* 72: 314–328. doi:10.1016/j.procs.2015.12.146.

Liao, Y., K. Dillenburger, and I. Buchanan. 2018. Does culture matter in ABA-based autism interventions? Parent and professional experiences in the UK and China. *European Journal of Behavior Analysis* 19, no. 1: 11–29. doi:10.1080/15021149.2017.1399657.

Lovaas, O.I. 1987. Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology* 55, no. 1: 3–9. doi:10.1037/0022-006X.55.1.3.

Mahmoodi, A., D. Bang, K. Olsen, Y.A. Zhao, Z. Shi, K. Broberg, S. Safavi, et al. 2015. Equality bias impairs collective decision-making across cultures. *Proceedings of the National Academy of Sciences* 112, no. 12: 3835–3840. doi:10.1073/pnas.1421692112.

Makrygianni, M.K., A. Gena, S. Katoudi, and P. Galanis. 2018. The effectiveness of applied behavior analytic interventions for children with autism spectrum disorder: A meta-analytic study. *Research in Autism Spectrum Disorders* 51, no. July: 18–31. doi:10.1016/j.rasd.2018.03.006.

Nickerson, R.S. 1998. Confirmation bias: A ubiquitous phenomenon in many guises. *Review of General Psychology* 2, no. 2: 175–220. doi:10.1037/1089-2680.2.2.175.

Nikolov, D., D.F.M. Oliveira, A. Flammini, and F. Menczer. 2015. Measuring online social bubbles. *PeerJ Computer Science* 1, no. December 2: e38. doi:10.7717/peerj-cs.38.

Nisbet, E.C., K.E. Cooper, and R.K. Garrett. 2015. The partisan brain: How dissonant science messages lead conservatives and liberals to (dis)trust science. *The ANNALS of the American Academy of Political and Social Science* 658, no. 1: 36–66. doi:10.1177/0002716214555474.

O'Connor, C., and J. O. Weatherall. 2019. *The misinformation age: How false beliefs spread*. New Haven: Yale University Press.

O'Neil, C. 2016. *Weapons of math destruction: How big data increases inequality and threatens democracy*. New York: Crown.

Pham, T., A. Kuznetsova, H. Gim, K. Cordrey, and R. Milanaik. 2019. The internet's effect on parental trust in pediatrician diagnosis of autism and likelihood of seeking a second opinion. *Journal of Autism and Developmental Disorders* 49, no. 10: 4355–4362. doi:10.1007/s10803-019-04140-8.

Procter, P.M. 2021. Patient care, information, communication and social media influencing bias—A discourse. *Informatics* 8, no. 2: 28. doi:10.3390/informatics8020028.

Proferes, N., N. Jones, S. Gilbert, C. Fiesler, and M. Zimmer. 2021. Studying Reddit: A systematic overview of disciplines, approaches, methods, and ethics. *Social Media + Society* 7, no. 2: 1–14. doi:10.1177/20563051211019004.

Saldaña, J. 2016. *The coding manual for qualitative researchers.* 3rd ed. Los Angeles: SAGE.

Sandoval-Norton, A. H., G. Shkedy, and D. Shkedy. 2019. How much compliance is too much compliance: Is long-term ABA therapy abuse? *Cogent Psychology* 6, no. 1: 1641258. doi:10.1080/23311908.2019.1641258.

Saunders, L., and J. Budd. 2020. Examining authority and reclaiming expertise. *The Journal of Academic Librarianship* 46, no. 1: 102077. doi:10.1016/j.acalib.2019.102077.

Shearer, E., and A. Mitchell. 2021. News use across social media platforms in 2020. *Pew Research Center's Journalism Project*. https://www.journalism.org/2021/01/12/news-use-across-social-media-platforms-in-2020/.

Shu, K., A. Sliva, S. Wang, J. Tang, and H. Liu. 2017. Fake news detection on social media: A data mining perspective. *Association for Computing Machinery: Special Interest Group on Knowledge Discovery in Data Explorations Newsletter* 19, no. 1: 22–36. doi:10.1145/3137597.3137600.

Southwell, B.G, and E.A. Thorson. 2015. The prevalence, consequence, and remedy of misinformation in mass media systems. *Journal of Communication* 65, no. 4: 589–595. doi:10.1111/jcom.12168.

Tasnim, S., M.M. Hossain, and H. Mazumder. 2020. Impact of rumors and misinformation on covid-19 in social media. *Journal of Preventive Medicine and Public Health* 53, no. 3: 171–174. doi:10.3961/jpmph.20.094.

Tschida, J.E., B.B. Maddox, J.R. Bertollo, E.S. Kuschner, J.S. Miller, T.H. Ollendick, R.W. Greene, and B.E. Yerys. 2021. Caregiver perspectives on interventions for behavior challenges in autistic children. *Research in Autism Spectrum Disorders* 81, no. March: 101714. doi:10.1016/j.rasd.2020.101714.

Vosoughi, S., D. Roy, and S. Aral.2018. The spread of true and false news online. Science359, no. 6380: 1146–1151. doi:10.1126/science.aap9559.

Walker, M., and K. E. Matsa.2021. News consumption across social media in 2021.PewResearch Center's Journalism Project. https://www.pewresearch.org/journalism/2021/09/20/news-consumption-across-social-media-in-2021/

Wang, X., J. Shi, and H. Kong. 2021. Online health information seeking: A review and meta-analysis. *Health Communication*, 36, no. 10: 1163–1175. doi:10.1080/10410236.2020.1748829.

Wilkenfeld, D.A, and A.M. McCarthy. 2020. Ethical concerns with applied behavior analysis for autism spectrum "disorder. *Kennedy Institute of Ethics Journal* 30, no. 1: 31–69. doi:10.1353/ken.2020.0000.

Yeung, A.W.K., A. Tosevska, E. Klager, F. Eibensteiner, C. Tsagkaris, E.D. Parvano, F.A. Nawaz, et al. 2022. Medical and health related misinformation on social media: Bibliometric study of the scientific literature. *Journal of Medical Internet Research* 24, no. 1: e28152. doi:10.2196/28152.