

Autistic and Accompanied: On Autistic Communities and its Literature

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Abstract. It is now widely recognized that the literature on the autism community, like the number of individuals diagnosed with autism spectrum disorders, has exploded in the last decade. In sociological research focusing on the autism spectrum community, even though landing on the same topic as they might be, the research questions of different authors are often diverse, fragmented, and disparate, and the relatively heterogeneous nature of both the research methods and the disciplinary contexts in which the research is rooted adds to the complexity of the situation faced by researchers wishing to provide an overview of the field. This paper attempts to provide a brief overview of the current state of research on the autism community by topic. The reviewed articles on autism communities are selected by keyword search and related literature search, and then organized and summarized in terms of research contents, research methods and reference values. The existing research on autism communities are arranged in terms of their coverage and database characteristics, in hope that doing so would point out possible future directions for researchers.

Keywords: Autism; autism community; stigmatization; caregiver.

1. Introduction

It is now widely recognized that the literature on the autism community, like the number of individuals diagnosed with autism spectrum disorders, has exploded in the last decade [1]. For researchers, this massive growth in the documentary has likely caused confusion and difficulties during the reading and selection of literatures. In sociological research focusing on the autism spectrum community, even though landing on the same topic as they might be, the research questions of different authors are often diverse, fragmented, and disparate, and the relatively heterogeneous nature of both the research methods and the disciplinary contexts in which the research is rooted adds to the complexity of the situation faced by researchers wishing to provide an overview of the field.

In the Chinese academic world, there are only a small number of studies on autism, and almost all of them are in the social work field about the burden of caregivers of autistic individuals. For example, Ni Chidan and Su Min studied 120 autistic families in Shenzhen and summarized the types of social work interventions needed by these families [2]; Gao Fei and Yang Jing focused on the burden of some families with autistic persons in Hebei Province and called for more of social interventions [3]. Within China, it is common practice to directly classify autism as a disabling condition and to simply apply the results of disability studies and social work approaches onto works about autistic persons [4]. In such an environment, the existence of a community consisting of autistic individuals are hardly visible nor valued, and individuals with autism with milder symptoms are likely to receive interventions and diagnoses late in their lives, sometimes never, as the absence of severe functional impairments usually impede them from realizing where the problem is, thus leading to a considerable part of their lives lived out in constant doubt about their abilities and identity. As for stigma research on autism, there are only a few Chinese studies on stigma for individuals with severe mental illness, especially schizophrenia [5], and the stigma attached to individuals with neurodevelopmental disorders is still an unrecognized problem.

With this in mind, this paper attempts to provide a brief overview of the current state of research on the autism community by topic. It should be noted that autobiographical literature, which takes the perspective of individuals on the autism spectrum and contains personal experiences and feelings, also constitutes an important part of material for researchers on the autism spectrum, but they are not included in the scope of this paper due to their abundance in number and their complexity. In addition,

although domestic sociological research on autism in China is in its infancy and the literature is relatively small, there still exists a certain amount of focused literature, the status of which will be briefly summarized in the conclusion part.

In this paper, articles on autism communities are selected by keyword search and related literature search, and then organized and summarized in terms of research contents, research methods and reference values. The existing research on autism communities are arranged in terms of their coverage and database characteristics, in hope that doing so would point out possible future directions for researchers.

2. Internet-Mediated Ties Making the Impossible Possible

The first question would always be: What is an autistic community? Until about twenty years ago, the concept would undoubtedly sound like an oxymoron; after all, one of the modeling characteristics of autistic people is that they are often hindered in social situations by difficulties in communication skills [6]. Both Bagatell and Kapp focus on the autistic communities that have emerged as a result of the Internet, and the former's observations and interviews demonstrate that the Internet can be a mere starting point for autistic people to make connections that would otherwise be considered impossible, but do not stop there [1, 7]. Like the organizing efforts Bagatell observed and occasionally took part in, they held their own events in autism-friendly venues [7], developed a collective identity as "auties", and often exhibited positive attitudes about their autism identity. This last point was also addressed in Kapp's large-scale questionnaire - another common misconception about the autism community and the neurodiversity movement is that it consists mainly people opposed to autism treatment [1], who form a secretive group, an impression not supported by the results of this study. According to the findings, neither autism identity nor neurodiversity supporter identity was associated with negative feelings directed toward behavioral interventions, while both are positively associated with positive feelings toward autism identity.

Another thing to be concerned about is that during the course of activities, the autistic community will undoubtedly need to meet a wide variety of other social groups at short notice, and even if there are few opportunities to have intimate contact at offline activities, one will inevitably come in touch with other internet users with different opinions during web-based forum activities and online discussions. According to Barker and Garlardi's crawling [8], analyzing and summary of the comments section of the New York Times Web article, reactions to an editorial about how the DSM-V tightened the diagnostic criteria for autism and combined multiple previously existing classifications into "autism spectrum" were diverse, with the majority of participants in discussions of self-reported autistic individuals and caregivers showed a similar attitude of opposition towards this change of criteria. It is notable, however, that only a minority (4%) of those who spoke out indicated that they were autistic themselves in their comments, far fewer than the number who indicated that they were autistic caregivers or relatives (20%) [8]. This may indicate that the opportunities and willingness of people with autism to speak out are relatively short in community discussions where a complexity of crowd involve themselves, even though the topic is closely related to autism. Although the reasons for this situation to have occurred are difficult to discern due to the nature of the study, it is clear that autistic people are still the weaker voice in public discussions on online platforms, in line with the view expressed by Bagatell's respondents that perhaps it is autistic people's "own" platforms and organizations that can give them a greater sense of freedom and security in the present situation [7].

3. The Caregivers and Their Communities VS the Autism Community

For those more familiar with the autism community, the relationship between the caregiver community and the community of autistic individuals themselves is not always as harmonious as the studies above suggest. The most common conflicts of opinion tend to happen between those who are

willing to seek and accept a “cure” for autism, and those who believe that autism is not a pathology and does not need to be homogenized by neurotypicals, but should rather be actively included in by this world dominated by neurotypicals. In particular, parents whose children have more severe symptoms and more impaired functioning are often more inclined to hold the former attitude. At least some caregivers, often misreading the demands of the neurodiversity movement and the autism community to a certain extent, believe that “Sadly they seem angry that we want to help our sick children and act like we hate them if we do” [1], despite their somewhat equally positive view of autism itself [9]. As an example for the latter point, even though they might organize and participate in parent support groups for autism intervention, some mothers of autistic individuals still believe that autism is not something that needs to be completely “cured”, and that their autistic children have their own unique strengths that neurotypical individuals do not possess [ibid.]. Furthermore, autism caregivers with professional backgrounds would reflect on what constitutes well-being for autistic individuals, and whether they should be treated exclusively as patients and thus benchmarked along with neurotypical individuals [10].

Indeed, the caregiver’s perspective is not interchangeable with the perspective of autistic person themselves in any case. Individuals with autism who are able to articulate their claims tend to be those who are less functionally impaired and have no or only mild intellectual impairment, whereas for autistic caregivers, their perceived caregiving burden is positively correlated with the severity of the care recipient’s symptoms and negatively correlated with the degree of intellectual impairment [11]. Those caregivers who struggle with the most severe functional impairments are under stresses that are difficult for any other group to experience. On the other hand, the vast differences between individuals with autism make the feelings and experiences of individuals with autism unique, and each individual has his or her own life experiences, which are not shared by neurotypical individuals or even other individuals with autism [12]. Despite this, most caregiver communities show supportive attitudes toward autism communities and activities, and the two rarely see fundamental differences in attitudes on various issues [1]. The caregiver community is often the closest, most potentially supportive, and an ally most likely to be calling for mutual understanding for individuals with autism. Thus, more future research should be conducted toward this aspect.

4. A Journey All by Oneself: Diagnosis, Biographical Illumination, and Identity

Many people’s lives as individuals on the autism spectrum begin with a diagnosis [12]. Those unfamiliar with the autism community may find it difficult to understand the significance of a diagnosis for members of this group: for many, it is a very important point in their journey to understand and reconcile themselves [ibid.]. More importantly, the diagnosis often symbolizes a sense of belonging: the diagnosis is often the first time that people on the spectrum begin to doubt, and then gradually move away from the “abnormal neurotypical” label, and start to accept themselves, embrace their identities, and find their place as a “normal autistic person” in the community of autistic people [13]. As mentioned above, “normal” is a high-frequency word in the research, and people almost always emphasize that it is only after their diagnosis that they begin to understand themselves as “normal”. This will be the beginning of their biographies, i.e., from the time they are diagnosed, they will realize step by step that their needs are indeed legitimate, then slowly come to learn to express them from their own perspective rather than doing their best to conform to the standards set for neurotypical people, with the latter often ultimately leads to harm or exhaustion [13].

At the occasion where they are able to articulate their own needs, autistic people’s demands outside the community rarely leave their need for recognition and acceptance. “Coming out” is one of the major issues that people with autism face in their daily lives. [14]. While trying to “come out” to others, individuals with autism need to find their own ways of making their neurodivergent condition known. Things would certainly be difficult for some of them, considering that the image of autistic persons is not always that fits with the reality. Despite the recent increase in autism-related written works, many fictional works still do not portray autism as well as they could [15]. In these works,

autistic people are portrayed as either geniuses or eccentrics, but are rarely (if ever) recognized as complex subjects of emotion with neurotypical people who happen to be authors and readers, and such stereotypes and false generalizations seem to add to the barriers to autistic people being understood and accepted. Both of these are relatively common encounters in the daily lives of autistic people, but their claims are seldom fulfilled, and go unnoticed more often than not. While many sociological researches focused on autistic communities and the identities of their members, few researchers have paid attention to these relatively off-the-wall, yet tangible, post-diagnosis issues that occur in people's lives, which is among the topics that need further study.

5. The “Autism Epidemic” and the Stigmatized Patient

Stigma is a concept introduced by Goffmann to refer to the negative impressions and evaluations that people form about individuals in their daily social lives solely because they possess certain characteristics [16]. The number of studies focusing on stigma in autism is currently rather small, but is by no means absent in the daily experience of people with autism. In addition to the aforementioned myths about the neurodiversity movement, individuals with autism are confronted in their daily lives with behaviors such as possible shifts in their attitudes and even deliberate social distancing after revealing their identity to those around them [14]. Liu, King, and Bearman showed that the geographic clustering of autism diagnoses increased with distance from the regular homes of children with autism in the school district [17], a phenomenon that might be attributed to an increased knowledge of autism, due to the presence of other children with autism in the local community. The increased awareness of autism due to the presence of other children with autism in the local community leads to awareness of the need for medical care and diagnosis. In other words, parents who do not have children with autism in their neighborhood are likely to be less aware of autism and the need of diagnosis and intervention, which in a sense confirms the persistence of ignorance about autism and the fact that such ignorance leads to the “epidemic” of autism.

In a study of stigma towards mental disorders, Link et al. defined stigma in terms of perceived dangerousness and social avoidance, and examined the factors that influence it separately [18]. Meanwhile, Link et al. also divided the stigma received by people with mental disorders into expected stigma and perceived stigma, and both had negative effects on the intervention process for people with mental disorders [19]. As mentioned earlier, it is clear that knowledge and impressions specific to autism also shape the diagnosis and intervention of autism, but there is a lack of research in this area. In addition, Corrigan et al. focused on the public's false stereotypes of the personality traits of people with mental disorders, introducing two possible models: that of responsibility (measuring the extent to which a person believes that people with mental disorders are responsible for their condition) and that of dangerousness (measuring the extent to which a person believes that people with mental disorders are dangerous and should be avoided) [20]. They found that contact with people with mental disorders was most effective in simultaneously reducing scores of stigmatizing attitudes in both models. In the case of autism, it is unclear what factors are present in effecting social stigma, or whether contacts with people with autism can eliminate stigma, but the above study's operational conceptions and analytical approach to the concept of stigma certainly offered an important reference for researchers yet to come.

6. Conclusion

The community is the core of social interaction for people with autism, and the diagnosis is the beginning of their personal lives as autistic individuals. This path of living as an autistic person involves “coming out”, struggling to understand and be understood, and fighting stereotypes and stigma among other difficulties peculiar to this group. Even with some of the “closest” ones to autistic persons, the caregiver community, misconceptions and even prejudices about the neurodiversity movement and the autism community are inevitably involved. For researchers, focusing on these

issues may not only uncover new and valuable findings, but may also increase the public exposure of the autism community, further public awareness and, if possible, facilitate access to neurotypical individuals, thereby reduce stereotypes and stigmatization of this group. Among all autism-related topics, there is a relative abundance of research focusing on community and interaction, but little research focusing on the microscopic, delicate social and emotional issues unique to the lives of people with autism are conducted. The research preference somewhat reflects the fact that the voices of people with autism themselves are relatively weak and often ignored by the society. In the future, researchers should perhaps pay more attention to the unique problems faced by autistic people, and the causes and solutions of these questions.

Compared to research in the English-speaking world, the Chinese literature lags behind in autism research, with a relatively small amount of literature, a relatively narrow field of study, and often limited understanding of individuals with autism. Under such circumstances, Chinese scholars can learn from the research approach of the English-speaking world, start with interprofessional and cross-disciplinary autism research, and rely on existing literature in other fields while selecting the rich research perspectives of prior studies. A descriptive and qualitative study of people with autism in the field would be wanted when researchers take the first steps. On the other hand, in the long run, Chinese researchers should also establish a more complete research system and literature pool while conducting quantitative research with large samples when the understanding of autism is relatively mature, so that newcomers can base their research on the data and conclusions of old studies, and propel more effectively the research progress of the field.

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