

Examining Online Practices of an Autism Parent Community in Turkey: Goals, Needs, and Opportunities

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ABSTRACT

Autism is a complex, life-long condition that manifests itself in unique ways in each person. Due to the complexity of the condition along with not having efficient and immediate social support, parents with autistic children often seek for and rely upon the information generated by the community (parents, caregivers, autistics and experts) on online platforms. We look into what parents of autistic individuals discuss on an online platform in Turkey, how they practice autism online and why those practices are important or relevant. Our findings show how parents cope with understanding and defining autism, and how they seek for empowering each other, and managing the everyday collectively under a dominant medical discourse around autism in Turkish context. Based on our findings, we extend the existing knowledge on collective and alternative ways of re-defining autism as lived experience and introduce recommendations on how those strategies can be integrated to design.

Author Keywords

autism, ASD; children with developmental disabilities; health information and communication; digital ethnography; rethinking medical discourse; caregiver; online communities; postcolonial computing; postcolonial health; global south.

CCS Concepts

•**Human-centered computing** → **Collaborative and social computing**; Social content sharing;

INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopmental, life-long condition signified by symptoms such as experiencing

social communication difficulties, sensory difficulties, having narrow interests and showing repetitive behaviors [5]. Due to these characteristics, autistic individuals¹ may face far-reaching challenges in daily tasks which consequently requires substantial support from parents, caregivers as well as society [33]. With each new challenge, parents of ASD individuals consult formally and informally with autism communities (other parents with autistic children, caregivers, experts). Everyday challenges that care communities of ASD face are diverse from medical [31, 19], educational issues [31] to everyday aspects [31, 14, 25].

Although previous work gives a detailed rendering of the ASD and the role of online communities for understanding, managing and helping the everyday of ASD individuals and the caregivers [31, 14, 33, 19], the majority of these studies concentrate on the situation in Europe, USA and Australia, including one example from Malaysia [31]. Further, in-depth studies on how the online platforms determine the everyday life of the ASD parents as caregivers remains less explored. To bridge these gaps in the area, we investigate one of the first and the largest ASD support and knowledge exchange communities in Turkey, a country where only very limited information is available online on ASD and related topics. Our analysis of the content on the platform disclose 3 themes on how the members (mostly parents) used the platform based on their needs and motivations. The ASD parents use the platform to (1) make sense of autism, its diagnosis and symptoms, including the reflection on how and when the definition connects to the everyday (2) to encourage parental determination and (3) to manage autism collectively.

Our contribution is twofolds. First, the study reveals how medical discourse acts as a core determinant to define the stories of everyday lived experiences of caregiving and of ASD parents. Our study compliments to the current literature on online practices of autism parent communities by extending the work to a less explored geography. We further discuss and illustrate

¹We are aware of the discussions on person-first vs. label-first language [28]. We use label-first version to respect the predominant self-chosen form. The definitions in quotes are left as is.

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how parents seek a counter balance to the determinant medical discourse through negotiating it and collectively re-defining autism through and by their everyday practices. Lastly, we show how geography specific strategies like spirituality, managing of a collective good mood, and civic engagement are used to help with the everyday of the ASD parental caregiving.

Current Perspective on Autism in Turkey

Based on the limited resources of foundations and the worldwide ratio of autism prevalence; it is estimated that 700.000 autistic individuals live in Turkey [35]. Public record is too weak, almost non-existent, and the state support is not systematic on issues around health, education, or further services.

The only scientific report on the issue is published by one of the biggest Turkish autism foundations in 2017, giving voice to the parents on their access to services and related needs is very limited, as it is mostly centered on the activities of specific foundation. As the report indicates, governmental considerations on the issue has been increased over the past decade and the interventions of the state become more visible [41]. One of the most prominent step that has been taken is the preparation and declaration of Autism Action Plan by the government [18]. However, there is no visible "action" that has been taken so far about the plan although the steps due by December 2019. As the report [41] also supports, social services provided (such as 12-hour special education per week) are limited and private institutions dominates the service domain. Due to lacking public records, information on autistic individuals who have and do not have access to educational or medical services is not available. In sum, the official information and legal support is hardly available, leaving around 700.000 ASD individuals and their families in struggle.

Given this context, our evaluation of the largest online support group is an important first step towards understanding the needs and opportunities of the ASD carers community in Turkey. Our study not only sheds light on everyday practices that are specific to ASD carers in Turkey, it also helps us to understand how an online platform can be driven by a dominant discourse (defended by a small number of experts), and how the same platform can act as enabler for collective care and as a space for empowerment to counter balance the dominant medical discourse.

Our aim is to capture the specifics of such communities to support designers with recommendations on how to design for balancing such tensions and for giving equal voice to all parties. In detail, the recommendations can help creating best practices for moderating online groups on controversial topics such as autism, balancing diverse experiences (parental, medical, everyday) and create awareness about risks of over-sharing.

BACKGROUND

Seeking Health Information Online

According to a report published in 2014 by Eurobarometer [11], 59% of European citizens use internet to search for health related information, of which 55% search for general health related topics such as lifestyle choices, diet, physical activity, 54% specific health conditions, 23% specific treatments,

and 10% search for a second opinion following their visit to doctors. Patients frequently seek online health information and share health related experiences as they strive for better health outcomes rather than being merely dependent on doctors' opinion[13]. Search engines are the main medium for such search, whereas 47-48% of patients use forums and blogs, 33% - 38% visit official health organization websites and 16%-23% look for information on social media platforms. A link between online health-related search and improved health outcomes was found (e.g. [8, 21]). Social media was helpful for improving users' access to health information [17], improving their health-related knowledge [4], offering a space where patients can find other people with similar conditions [30], seeking social support [4], exchanging advice [4], discussing their symptoms, experiences, needs, treatment options [30], helping in doctor selection [30] and having an efficient doctor-patient communication [4]. Still, there are concerns about the accuracy of online information [24, 4], and thus, investigating the relation between social media and health seeking information is crucial [30].

Online Communities and Informal Care

Online health communities for informal support and care are plenty [1, 22, 32]. The most significant benefits of such communities are: raising public awareness on disease prevention [10, 44], encouraging patients to keep searching for treatment, fund-raising [10], information seeking, and emotional support and community building [44]. From the individuals perspective, peers' insightful disclosure on an online health condition community is proven to reduce negative emotions and boost well-being of group members with the same health condition [38]. A discourse analysis study on a self-help online community of caregivers of people with mental illness has shown that disclosure, providing information and giving advice were the prominent focus of the messages users share [36].

The community members' experiences on online health platforms are important assets that define the design of such platforms. Recent platforms include a broader range of participants, including informal caregivers, parents and other experts. They need to support multilevel interactions (e.g. between experts, parents, and individuals facing a chronic condition), creating an extended space that accommodate all perspectives from these diverse participants.

As design considerations to such platforms, previous work from related field of aging and care provided design opportunities such as using tag systems to build common knowledge, and practical solutions to access to social support effectively for older informal caregivers [40]. Anonymity aspect that is to be provided by online platforms was also found important in disclosing health issues, especially in sensitive and stigmatized conditions [6].

Online Parent Caregiver Communities

Having a child with special needs is considered expending more effort and resource than having a child with typical needs [15]. Parents as caregivers of children with special needs mostly rely on internet for information, resources and social

support [3]. They are actively online for: searching health-related information [3, 2], creating content about their children [2], and seeking social support [3]. Facebook groups (on preterm infant care) serve as an important tool in terms of providing interpersonal support, sharing information, fund-raising and creating awareness [39].

One shortcoming of current systems is the inefficiency of websites in connecting experienced parents with less experienced parents; which can be improved to enhance interactions in social media support groups [3].

Online Autism Parent Communities

Previous studies focused on online discussions around autism in general [6, 31, 33], online accomplishments of parents and autistic individuals [27], and the benefits of such online platforms [14]. Parents and autistic individuals use online boards, forums and blogs for exchanging articles, reducing isolation and advocating for autism [27].

The findings from such studies include: a relationship between autism and parental identity [19, 14], a wish to support others in Facebook groups [19, 14], ways the platforms support members on understanding autism, adjusting the changes and search for meaning [25], managing of behavioral difficulties [9], to extricate themselves from their isolation through the online connections [14]. The online services further act as emotional support for caregivers [9, 31, 25], and informational support for parents [31]. Further, being in a parent caregiver support group is a valuable resource of insight for practitioners [9].

In sum, previous work gives an overview of the functions of similar online platforms [27, 14, 9, 19], the discussion topics in such platforms [33], and the types of support and exchange [9, 31]. The most prominent potential of those platforms for autism parents can be stated as social support [9, 31], getting help from other parents [14, 31], reduce isolation [14, 27, 19], experience sources and informational support [27, 31], experience stress related symptoms while extricating [14]. The weaknesses of these communities have also been reported such as spreading inaccurate information among users and slowing the progress of autism movement [27].

Through different types of analyses on various online platforms, previous research have provided an important account on what parents of autistic individuals give in, discuss and get back on those platforms, online interaction patterns and discourses around interactions. However, current research literature is less sufficient to provide a sophisticated and detailed account on the roles of such functions of those platforms in diverse contexts and localities on understanding and shaping the collective online discourse around autism and its care, especially from a parental caring perspective. We believe that having a closer look into in which ways such platforms are used to build and discuss this crucial stance can be beneficiary for both parents with autistic individuals, and for the broader communities.

METHOD

To take a closer look into how online communities on autism from a diverse locality and through parents' perspective work, we conducted an exploratory digital ethnography (see [37]) study on a Facebook group in Turkey, a reflexive study of a digital platform usage without a digi-centric approach. Facebook and its use for health related issues have been prominent in the last decade. For example, 23% of the Facebook users from the U.S.A. follow friends' personal health experiences or updates, 15% seek to retrieve health information, and 9% joined a health-related group [16] on Facebook. Facebook has a valuable potential to influence behaviors of individuals around health related issues and improving their access to relevant health related information [32]. For our study, we chose the most crowded (22.459 members) and active (in terms of number of posts, comments and likes) autism group on Facebook in Turkey.

Ethical Considerations and Procedure

Since it is a private group, members are required to send a request to the group admin to join the group. Requests are being accepted or declined based on the applicants' answers to the following questions: in which ways the applicants are related with autism and why they want to join the group. Each member has access to the entire content of the group upon acceptance.

The content of the group is created and organised mainly by self-identified parents. There was only one user self-identified as autistic, and there were people who introduce themselves as special education teachers and therapists. All members are allowed to post or comment on the posts without restrictions. Still, the majority of interactions takes place between parents. Other experts (from education, medical, psychology domains) are rarely explicit, and they only occasionally get involved in the discussions. Prior to this research, we, as researchers, passively observed the interactions in the group. There were rare instances, where we commented on the posts (e.g. a question left unanswered which we thought that we could contribute).

The content collected for the analysis includes all the posts and comments from a full-month in 2018 during the school period that was chosen based on recency. During the data collection, we chose not to actively post or answer any questions on the group. We used an opt-out procedure in sampling. As it is a private group the opt-out method were used meticulously in applying necessary steps about ethical requirements. Ethical approvals were obtained from the university's ethical committee and we applied the following steps:

- Two of the authors joined the group by clearly stating that their relation to autism is research-based and they are willing to become members of the community to see discussion topics for research.
- Upon acceptance, researchers sent a direct message to the admins of the group via Facebook, who are responsible of managing membership requests, and took their consent for the research.

- Researchers posted a detailed explanation of the study, its aim and procedures to inform the members of the group. Following an opt-out procedure, members were given one week to inform the researchers in case of not being willing to allow researchers to collect and analyze the content they created within the chosen time period.
- To protect members' privacy, all the names (name of the group, user-names and all the names provided in the content such as names of people, companies and autism associations etc.) were changed with pseudonyms as seen in Findings section.

Data Analysis

All the content (posts and comments) shared during the selected period were gathered in screen shots and printed out to create the data-set for the analysis. We included the comments in the analysis to capture the communication flow and interactions. The content were qualitatively analyzed using inductive thematic analysis[7]. Two researchers worked independently on two separate print-outs. Initially, researchers took notes on each thread (post and comments), highlighted the main topic of the thread and gathered keywords. After identifying and agreeing on discussion topics, essential themes that reveal the functions of the group for the users were discussed. Lastly, the themes were further reviewed by two other researchers in collaborative analysis sessions.

FINDINGS

We spotted 141 posts and 5487 comments in given time-frame. These content were created by over 300 users consisting of mainly parents. We identified 3 main themes and 4 sub-themes (see Table 1) regarding the functions of this online community. Below we explain our findings.

Making sense of autism

One notable function of this online group is that it serves as a space for parents of autistic individuals to discuss autism in terms of its meaning and causes, diagnostic processes, symptom management and ways to comprehend and explain it.

Diagnosis and symptoms:

We noticed that this Facebook group is one of the first touch-points that the parents with newly diagnosed children as well as parents who think their children may have autism interact with. There were 10 posts specifically referring to receiving a diagnosis. These posts included discussions on what the autism diagnosis mean, how would they be able to spot autistic symptoms, how they would be sure that the diagnosis that they received is an accurate one or whether they need extra opinion, whether they should get a medical report, what the meaning of diagnostic percentages in medical reports is. These questions were the main struggles of parents that make them seek for others' experiences on the platform. Quotes below exemplify such instances. Type of the content (post or comment) is given in parenthesis after each quote.

Dilara: The psychiatrist told me that my child won't be able to talk. I did not even understand what he meant by that. Anyways, I can't accept this. I care about the

experiences of other parents. Do your children talk? That's what matters to me. (post)

Ali: My daughter has received the autism diagnosis recently and has started special education school. But the psychologists at the school said that although my daughter may show some autistic symptoms and has 'hints of autism', she is not an autistic and we can overcome those symptoms with education. Now I'm thinking that our doctor might have misdiagnosed her and we should see another doctor. I am so confused! What would you suggest? I wish God would help us all. (post)

Derya: It doesn't matter what different experts say. If you notice differences in your daughter's behaviors, work on those symptoms and support her. Don't care about the diagnosis. If the diagnosis is wrong, you'll find it out one way or another. (comment)

Most parents who commented on the questions about diagnosis, suggested a common approach: working on the behaviors through special education without losing time trying to receive an absolute and final diagnosis. Besides receiving a diagnosis, parents use this platform to discuss how to make sense of their children's behaviors as well as how to manage them. The behaviors that they seek solutions for were eating (5 posts), sleeping (3 posts), social behaviors (2 posts), verbal communication (3 posts), motor behaviors (3 posts) and destructive behaviors (5 posts). Parents generally shared a post regarding one of these behavior problems, asked for possible explanations and similar experiences, and looked for solutions, as seen below:

Deniz: My son eats almost nothing. We have serious problems with his eating habits and he never wants to try anything new. Did anyone experience that before? What would you suggest? (post)

Umut: There is a diet called GG. It is very effective, give it a try. It is like cure for autism and all the symptoms, including eating problems. We have overcome many difficulties thanks to this diet. (comment)

As illustrated by Umut's comment, parents shared their own practices to specific problems and their insights with other parents. The solutions and suggestions varied from making minor adjustments to daily practices such as "making the kid stay away from TV" to intervening social behaviors and to more complex practices such as "changing own perceptions about the difficulties that the child experiences".

Similar to Umut's comment, numerous other one-fits-all suggestions were made for the problems in children's behaviors. However, we also spotted comments where respondents asked for further information from the parent who raised the question (e.g., age of the person with autism, specifics about the behavior that was subject to the question) to make more personalized suggestions rather than generalizing. Some users added videos and pictures to their posts to communicate their experiences better:

Sule: My daughter is trying to sleep as you see in the video, but she also resists falling asleep. Something's happening to her during sleep, she wakes up and gets

up suddenly and starts crying. Anyone experienced that before? (post)

Hatic: *She might be experiencing physical problems. See a doctor immediately.* (comment)

Muhsin: *Before she goes to bed every night read this [providing a spiritual text] to her. This would make your daughter relieve.* (comment)

Although we only spotted 3 posts that users raises questions centering upon sleeping problems, they received noticeably high reactions. These posts caused major discussions and exchange of ideas when someone shared their children's sleeping problems. For example, by the post above, Sule triggered a complex discussion where people talked about many other topics around sleeping problems such as medicine use and side effects, diets and special nutrition, possible psychological traumas and alternative solutions such as religious practices to ease difficulties.

Reflections on autism:

We identified 17 posts including parents' interpretations of autism. Their reflections revealed how they understand and make sense of autism, and how they relate autism to other disorders and the concept of disability. We detected an apparent confusion in medical categorization of autism: whether it is a disease, or a type of disability, or "*a different way of perceiving the world*". Related with that, there were also different opinions on the permanency of autism, whether it is a lifelong disorder or a disease that would be cured eventually. We came across statements such as "*our knowledge about autism is less than our knowledge about Mars*" referring to the still unknown nature of autism that makes parents confused and bemused. In one of the related posts, which also sparked an intense discussion, a parent asked about how to communicate the concepts (autism, disability, special needs) to their children:

Ekrem: *My son with autism has been going to a special education school for 7 years. But nowadays, he says that he doesn't want to go to a special education school anymore because he is not disabled. As he grows up, he starts to realize things. How should we approach and explain this to him?* (post)

To this question, parents shared their experiences in how to explain their child the "*meaning of autism*" or "*being an autistic*", or the fact that they need special education. Some parents suggested to highlight the "*positive sides of the diagnosis*" and that those kids are "*of course not disabled*", "*different, but superior than typical kids*", "*unique*", "*special*", "*angel*", "*not insufficient, but may need extra support*". These expressions illustrated how parents interpret autism and therefore how they communicate it to their autistic children. Two parents stated that their kids dropped out of the special education school because they could not explain the necessity of special education to their children on the spectrum. Also, we encountered 2 posts where users announced seminars targeting families of autistic individuals, and one of them was specifically on inter-family communication for parents.

Encouraging parental determination

Another prominent function of the group was sharing own stories and encouraging each other in the practice of taking care of an autistic individual. Parents also used the group as if it is their personal Facebook page, sharing photos and videos of their children and themselves. We spotted 20 posts where parents shared their children's videos. 13 of these posts were showing an achievement of their children such as playing the piano, singing a song, riding a bike or receiving a diploma, mostly with a remark highlighting how the child succeeded in related activity and how parents enabled that. They laid emphasis on their determination on the progress to encourage other parents to show strong determination, wishing similar accomplishments for them. As a reaction to these posts, respondent parents celebrated the achievement (mostly saying "*masallah*"), which is a special spiritually charged term that reflects admiration and support) and the determination. Sharing a video from a year end show where his daughter was playing a video, a parent posted the following:

Nazan: *I am intentionally sharing the video of my daughter playing the piano here, so that other parents could understand that every child with autism can achieve things with patience, education and hard work. We were rejected by many schools and teachers, we cried a lot. But we did not give up, and we have made this achievement possible.* (post)

Fusun: *No effort goes wasted. I congratulate your child as a proud mom whose daughter has also made an unexpected progress.* (comment)

People also shared their appreciation on other parents' determination highlighting the "*endless love and effort*" they give to their children and wishing "*great rewards from God*" to those admirable parents. We observed a pattern in dealing with everyday problems, getting effective medical support, providing and supporting good education, and seeking change in organizational (foundations) and governmental levels (policy change) through emphasizing "not to give up" and strong determination; as seen in the following comments: "*I believe you'll see the days your son doing really good, keep working. Maybe he'll be fully cured*" and "*I wish God help you and give you patience*".

Making attempts to build communities of practice:

There were several instances where the online group functioned as a platform for parents to practice as a community and create meaningful social support for each other through encouraging determination and providing emotional support on daily problems, struggles, confusions and achievements. Despite the broad range of interests and discussion topics, posts about negative social experiences were prominent and received a significant degree of responses. 6 posts included daily social life struggles with children due to society's reactions. Following posts illustrate the explicit articulation of such struggles:

Bengu: *People got me down again. Believe me our kids are more normal than other people around whom we call "normal". A cleaning lady at the school yelled at my*

son and threatened to beat him. My son is not even able to understand her and defend himself. I am so angry. People are incapable of understanding our kids and us. (post)

Mehmet: *Society is uneducated, unaware and unfair. We should take action against such situations.* (comment)

Berrak: *Nobody understands why my kid behaves the way he does. I don't see my family or neighbors anymore. They don't want to visit us or let us visit them. I don't bother myself trying to spend time with people anymore. Actually, I think we should visit each other instead!* (post)

These instances sparked discussions on being isolated and receiving negative reactions from the society; yet very few comments were made to call for community practices (visiting each other, taking action, acting collectively). There was 1 post where a user announced a dinner event organized by an autism foundation, which got no reaction from the users. Other than the collective meeting announcements, we spotted 3 posts for individual network formations where two users arranged an occasion to talk in private by exchanging phone numbers or deciding to talk via direct messaging. Although clear majority of the users were parents of autistic individuals, there were also active teachers and students (who were identifiable through their user names and interactions). We spotted 2 posts where students shared surveys targeting parents. Those posts received positive reactions from parents including their suggestions for research topics, indicating attempts to practice as a community involving different people related to autism in different ways.

Managing autism collectively

Parents used the group to evaluate and seek for advice about existing services related with autism. 23 posts were about educational services whereas 15 were about medical services. Through sharing their experiences about the services they tried, good and qualified ones become more visible to parents. The discussions on educational services consisted of how to choose and where to find good schools and teachers (13 out of 23 posts) including questions such as "*Any special education school recommendations?*". Through sharing their experiences, parents compared the effectiveness of education at school and homeschooling, public schools and special education schools, and discussed the integration of autistic kids to public schools, the quality of special education schools and teachers, insufficiency of free special education provided by the state, how to approach educational processes and what to expect from special education services.

Huseyin: *My son's first lesson with the special education teacher was this morning. They played a simple game which he was already able to play way earlier. How is he going to make my kid speak with these foolproof games? I'm starting to think that special education is just nonsense.* (post)

Elif: *It is not nonsense. Sometimes there are problems with the way it is practiced. My kids have started to gain many skills thanks to special education.* (comment)

Yasemin: *I agree with you Huseyin. Kids can't learn if they just don't have the gene for learning. In that case even a full day of special education wouldn't help.* (comment)

Beyza: *Be patient, Huseyin. Teachers assess the skills the kids already have through the first lessons. Don't be prejudiced and hopeless so quickly.* (comment)

As seen in the thread above, parents' experiences with and approach to special education varied and contradicted. They also exchanged ideas about what to expect ("making the kid speak") and how to expect ("being patient") from special education system and from the teachers.

A similar dynamic existed in the experience exchange about medical issues. They negotiated ideas about finding doctors and appropriate medication (what to use, how to use) for their kids with autism. There were 7 posts (out of 15 posts about medical services) where parents asked for specific medication, seeking information from other parents about the possible side effects and benefits of the medication that their doctor suggested. They also asked about the usage, referring to appropriate dosage and frequency.

Besides qualified services becoming more visible to parents through evaluations, they also become more accessible to them because parents exchange suggestions and tools about how to access and make use of those services, as the following instance exemplifies:

Bihter: *I called the hospital many times to get an appointment from Dr. Havva but couldn't yet. I guess she is so busy. Does she work somewhere else too? How do you get an appointment from her? I need to travel a lot with my kid to talk with her.* (post)

Kemal: *Right, it's so hard to get an appointment from her. You need to call the hospital again and again. Also there is an application module called MS, where you can see her schedule easily and try to get an appointment.* (comment)

In terms of accessibility of those services, financial difficulties experienced by parents was also prominent (9 posts referring to financial difficulties across education and health services related posts). Parents addressed the insufficient state support through the discussions on inaccessibility of high quality education and health services, and how that leads to an unbearable financial burden for them. Despite the availability of numerous schools and doctors, parents highlighted their dissatisfaction with the services originating from financial inaccessibility and huge demand.

Seeking change:

There were 3 posts where users posted petition campaigns on making the services free to change the financial burden they are facing. Further, we encountered 15 more posts where users shared campaigns to make their demands visible to the government and policy makers. Through these campaigns, they showed their expectations in new and improved policies and also activation of already proposed plans (referring to the Autism Action Plan). They used the slogan "*this is*

FINDINGS	Making sense of autism -diagnosis & symptoms -reflections on autism
	Encouraging parental determination -making attempts to built communities of practice
	Managing autism collectively -seeking change
DISCUSSION	Medical discourse as a core determinant -collective re-definition of autism -negotiation medical discourse -empowerment within medical discourse through spirituality and good mood through civic engagement

Table 1. Themes and sub-themes in findings and discussion.

not enough" when sharing campaigns on the insufficiency of already existing and accessible services for autism. In one post, parents talked about a specific institution highlighting its unwillingness to help parents to create change:

Derin: *The [foundation] don't take families' needs and purposes into account. I know many people thinking the same about the [foundation]. I want this to change! Let's take action and file a complaint.* (post)

Ekrem: *They [foundation] claim to be a non-profit organization but they obviously make profit by our helplessness. What do they actually do for us? I individually filed complaints about them to the authorities many times, but this needs to be a collective act.* (comment)

As the captions above and the *this is not enough* campaigns exemplify the need for change in organizational and policy level, this platform functioned as space to make critique of what is offered for them. Through evaluating the education, health services, foundations and policies, they exchanged ideas on how to improve those and what they want to change.

DISCUSSION

Our findings have drawn parallels and extend the literature on understanding online autism parent communities [14, 25, 33]. From an autism parent community case in Turkey, we discuss how the medical discourse act as a core determinant in the everyday of parents, and how they cope with the unbalanced situation by responding using their beliefs, cultural practices and social support mechanisms (see Table 1). Our findings have showed diverse notions of use of an online platform by the autism parent community. Most importantly, our findings have indicated that the platform has been used to discuss and live autism in diverse aspects. This can be best explained by the nature of autism causing various levels of differences in multiple contexts. Autism is a spectrum, which generates diverse experiences, symptoms, treatment methods, levels of progresses and approaches between those who are on the spectrum. Besides, autism is a complex diagnosis due to different hypotheses on its causes and all those leads to the fact that one-size-fits-all explanations and treatment methods is not

useful and applicable. This situation might be an important motivation for autistic individuals and parents to seek for experience of others. In our study, where no knowledge and support systems are available and pre-given e.g. by the state or by public organizations, many instances of ASD was organized by people with an holistic approach. In the following part we will discuss these in detail.

Medical discourse as a core determinant

Recurring domination of medical discourse on online discussions of autism parents has been striking in our findings. Medical discourse is a core determinant that shapes the tone of the interaction among users. In broadest sense, medical discourse *"is a discourse in and about healing, curing, or therapy; expressions of suffering; and relevant language ideologies"* [43]. According to Lalvani et al., the dominant discourse on the parents of disabled individuals significantly influenced by medical perspective [29]. The ASD diagnostic criteria and the medical lens on ASD, is still continuously being defined, leaving people in or outside the spectrum (see discussions on false autism epidemic online [20]). The determination and domination of a medical discourse -that is still on the making- is a limiting perspective as it oversees the facets of the lived experience, and reduces the complexity everyday of living with autism to a single definition. Autism is not a "disease" but a lifelong condition that depends on symptom management and skill acquisition with a lifelong support rather than healing, curing or therapies.

The domination of the medical discourse was clear, but also perceived as a drawback in online discussions. We spotted alternative and individual perspectives of parents on autism. Examples of alternative discourses arise within dominant discourses (e.g. medical discourse) are also available in self care and aging contexts [34, 42], pregnancy support communities [23], next to the discussions in disability [29] and autism [12]. Our findings have uncovered that the platform acts like a mentoring place, giving collective advice on each individual problem, making attempts to generate alternative discourses on how to cope with the autism and dominant medical discourse on autism. Coping is a broader issue than "healing", as it includes multiple perspectives and strategies. Here, we present 3 different ways of parents coping with the medical discourse: collective redefinition of autism, negotiating medical discourse and empowerment within medical discourse.

Collective redefinition of autism:

Through personal reflections on definitions, we observed instances where parents struggle with the categorization options that the medical discourse provides (e.g. disabled, typical, autistic, diagnosed, normal) and find ways to come up with new definitions such as *different, superior, special, need support, more normal than whom we call normal*. Although parents refer to their children as autistic or disabled in many instances, we also see generation of new and personal definitions that especially become visible when it is about communicating the diagnosis with their children. Examples in the findings (see reflections on autism, making attempts to build communities of practice) show such struggle between personal definitions and predetermined medical categories.

Those reflections both exemplify the lack of resources about the definitions and shows us how families create a space for collectively seek for alternative definitions.

Negotiating medical discourse:

Through the discussions on the diagnosis, we see parents' reflections on their first encounters with the medical instances. Less experienced parents who suspect their children's behaviors might be related to autism, or parents who are unsure with the diagnosis received, seek for other parents' opinions. Due to lacking resources on the topic, parents are in constant tension with the expertise. The expressed mistrust in findings is not necessarily a result of lack of expertise. It is rather a result of tension between the parents and resources. In order to cope with the controversy that arises from different experts and the tension that arises from lack of clear answers in the medical diagnosis process, online community is used for making sense of medical diagnosis. Here, distinguished bottom up explanation from parents is to get beyond the diagnosis step quickly to focus and work on the symptoms (see: making sense of autism). Beyond what experts say (e.g. "not able to speak"), parents seek for similar experiences on the process or alternative explanations.

Further on symptoms, medical discourse dominates the discussion on making sense of and coping with symptoms in everyday situations. While parents seek for similar experiences to cope with their own experiences, some ideas are exchanged between parents, such as "miracle solutions" and "cures" that can treat the condition or erases the symptoms. Those solutions for "all the symptoms" or "all autistic individuals" are the reflections of the generalizing nature of the medical discourse. This is in contrary with the nature of autism as a spectrum, reducing diverse and unique experiences into a one size fits all solution.

At the same time, this experience exchange on symptoms can be interpreted as an individual act, considering users seeking solutions for each issue they face individually. Through sharing personal stories, coping mechanisms and ways, parents search for bottom up, alternative and individual interpretations on managing symptoms. They negotiate their experiences on medications (e.g. negotiating ideas about medications that doctors suggests) and create a space for alternative solutions beyond changing the autistic individual but changing their own perspective as parents and perspective of the society (see: makings sense of autism, encouraging parental determination). Through those individual posts, a collective opinion and definition getting built on different issues.

While discussing services, a "therapy" point of view of medical discourse that aims to heal, cure or normalize seems to determine the expectations of families for other not directly related services, education and health related services (discussions on impact of genes vs. effectiveness of education, special education for making the kid speak). Our results also show an apparent tension on services (see: managing autism collectively). This may be explained by insufficient state support on health and education and therefore domination of private practice based services.

Empowerment within medical discourse:

Within inductive and generalizing nature of medical discourse, autism parents seem to empower each other through different strategies which are good mood and spirituality, and civic engagement.

Empowerment through spirituality and good mood: Our findings show many instances where users empower each other through good mood and spirituality and use this to cope with autism within the dominant medical discourse. Users offered spirituality based practices (e.g. suggesting a spiritual text) to each other to cope with the symptoms. Also, users use spiritual statements and terms to reflect their support ("maşallah", wishing patience and great rewards from God) and empower each other going beyond medically charged discourse.

While showing support, users mostly encourage each other by approaching a positive and hopeful mood on living with autism. Although the success stories of their children and achievements might be arising as reflections of medical discourse (e.g. making generalizations) and its predeterminations, in some of the instances parents create a space where they focus on individual talents of autistic individuals and importance of supporting those beyond the predetermined expectations.

Empowerment through civic engagement: Our research highlighted how parents go beyond negotiating diagnosis or everyday symptom struggles and further discuss autism in relation to society and politics. The discussions that aimed for the mobilization in the community and create meaningful change in policy level showed how the interpretation of the lack of resources helped to initiate civic engagement. Even if the discussions didn't end up with a fully integrated civic engagement plan, the participants empowered each other in terms of seeking for more collective and far reaching change in social space (awareness of society, foundations) and political approach and practices (e.g. seeking the activation of Autism Action Plan).

Relevance to Turkish context:

Our work aims "to expand the conversation around cross-cultural" understanding of autism parent communities by placing it "in a broader context", where we see ourselves to settle in the postcolonial discourse and not in the development discourse [26].

Still, we came across to the instances specifically meaningful within the Turkish context. The opinions on Autism Action Plan are visible through the users' posts on issues like: "seeking change", struggles on insufficiency and accessibility of services ("this is not enough"), financial burdens due to that insufficiency or tension between foundations and families (see: managing autism collectively). This can best be explained in relation to currently limited state support and public support for autism in Turkey.

In relation to coping with the medical discourse, the frequency of practices of collectivist nature, strategies used for empowerment, and the use of spiritual advice and wishes may as well be in correlation with the specific cultural context.

To contribute to the broader context, this study is one of the earliest examples for looking into online autism parent communities in Turkey. Our work contributes to the previous research on online autism parent communities and on caregivers of children with developmental disabilities by extending the literature on how autism is lived and shared online in Turkey. We introduced the dominance and determination of the medical discourse in the online interactions of parents of autistic individuals and thus extended the previous knowledge on recurring medical perspectives in other online support communities on (e.g. pregnancy [23]) to the context of autism. By providing alternative discourses created by parents based on their practices shaped in Turkish context, our results also showed a set of bottom-up strategies, such as a collective set of acts to cope with "autism" and "the medical discourse" around it in everyday.

Relevance for HCI & Recommendations

In a context of scarcity of resources and services and weak public support, we believe that the practices of ASD parents in this online community give us the opportunity to re-think how such online platforms can better integrate the complex goals and needs of the members. This made us ask further questions about the functions and the nature of online platforms and online support communities, in relation to autism, medical discourse and HCI.

Previous literature pointed to the core functions of an online autism community as: managing behavioral difficulties [9], providing emotional support [9, 31], informational, esteem and network support [31], raising public awareness [27], develop and forge interpersonal relations and manage their isolation [14]. Our findings extended this discussion to the importance of the online community for making sense of autism, encouraging parental determination and managing autism collectively.

Parents of disabled individuals challenge and complicate the assumptions presented by medical models by counter-narrating their experiences [29]. According to Jordan, internet has opened a discourse and allowed raise of diverse opinions in autism community rather than domination of exclusive voices [27]. Our study also supported that parents create bottom-up alternative discourse on autism within dominant medical discourse, through online interaction and digital platforms with several strategies. In addition to present importance of passing knowledge between diversely experienced parents [40], our work showed that the diverse users collectively generated an alternative discourse around autism, that is shaped by their motivations, everyday practices, and the collective understanding of autism in Turkey.

Our recommendations from the field can be necessary for digital platforms that manage similar content. Our suggestions for designing digital platforms to support parents with special care duties are as follows:

1. be aware of a possibly dominant medical discourse and create a space to effectively negotiate ideas, personal solutions and strategies, personal stories and learn through each others experience. A life course approach instead of a singular medical perspective would allow alternative discourses. In

line with the recommendations of Gui et al., focused on an online peer support community around pregnancy, online health communities should consider opportunities for better archiving, indexing and recommending knowledge that comes from experience [23]. Alternative discourses can be highlighted in this community through similar interventions that Gui et al. have suggested.

Further, online communities can explicitly seek for and welcome experts from diverse backgrounds (eg.:designers, architects, or even writers of children books) next to medical experts and allowing the negotiation of the medical discourse from all perspectives including personal beliefs, or everyday instances and experiences.

2. be aware of a need of the users to re-define the designed platform and its uses, to collectively re-define autism. Avoiding a pre-given static definition, making such collective acts visible (via polls, weekly admin commentary), encouraging the participants by giving them feedback on what and how they are shaping, the platform can encourage the effort on creating such bottom-up new definitions.
3. realize the ways how users empower each other through unique ways. Being aware of and responsive to such practices, platforms may offer extra tools to boost those (more reflective emojis to express how a user affected by a shared information/experience in a personal way, or buttons to answer with spiritually charged expressions may be some opportunities). Sharing personal stories that reveals diverse progresses and narratives on autism and positive interactions around those should be encouraged (eg.: via gift vouchers, some real life bonuses to the ones who share).
4. boost users' attempts to enable the mobilization of the community through developing civic engagement and supporting each other on developing that. Platforms might highlight instances where users practice civic engagement (e.g. through sharing petition campaigns) and seek for each others support on those in order to claim change. Platforms might be supportive to make these bottom-up demands and collective voice visible to actively support the community to take meaningful action.

Primary strength of our study is on how it reveals the dominant and determinant role of the medical discourse in defining the stories of everyday lived experiences of caregiving and of ASD parents in Turkey, a country where only very limited information is available online on ASD and related topics. Three main themes and four sub-themes that emerged from the data are: "making sense of autism" which includes diagnosis and symptoms and reflections on autism, "encouraging parental determination" includes making attempts to build communities of practice and finally "managing autism collectively" includes seeking change. In discussion we highlight the domination of medical discourse which determines the tone of interaction and also provided the ways parents engage to cope with the medical discourse through collective redefinition of autism, negotiating medical discourse and empowerment within medical discourse embracing spirituality and good mood and civic

engagement (see Table 1). Finally we propose 4 design recommendations for online platforms to support parents with special care duties.

CONCLUSION

Our study is grounded in a context where the resources are limited and state support on autism is nonfunctional. Our results indicated to the ways of coping with such scarcity, the dominant medical discourse, and other everyday challenges by negotiating and collectively re-defining the autism discourse online. In many instances, our study revealed both the recurring domination of medical discourse that stands as a drawback and the mechanisms of parents to cope with and re-balance the situation.

Allowing both medical and everyday expertise on the same platform open up a new space for giving voice to all perspectives of the parents. Digital platforms do not only provide a social context for interaction, but also produce everyday forms of collective knowledge. Based on this, we provided four recommendations from the field for designing interactive systems for similar communities.

One limitation to our study is having only the digital perspective about the lived experiences of parents. Our findings from this work revealed several new aspects about parenting and autism that are partly specific to Turkey (the coping mechanisms) and contributing to the current global debates (eg.: a dominant medical discourse). In future work, building on the discussion on medical discourse and alternative discourses, we will be extending our research to an ethnographic fieldwork for revealing parents' lived experiences.

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