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"I Learn Here What I Don't Learn Anywhere Else": An Analysis of an Online Healthcare Community

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Abstract

This article aims to analyse the dynamics underlying communication within an online health community focused on carers, titled "Vencer Autismo" (Overcoming Autism). The community's central platform was a Facebook page, supported by a weekly live programme moderated by moderators. A qualitative research approach was adopted, employing digital ethnography and interviews. The empirical study spanned over nine months, from September 2022 to May 2023, with the primary phase consisting of ten weeks of digital ethnography, followed by 10 interviews. The analysis of the relationships between identified elements revealed that the knowledge shared within the community is viewed as rare by its members. This knowledge is based on lived experiences, with an emphasis on practical learning, testing, and irreverent discourse. Regular interactions were found to strengthen relationships, while the sense of inclusion served as a unifying force. Trust, another key theme, was found to be volatile—and in constant development — reliant on minimal factors such as moderators refraining from commenting on topics outside their expertise. Transparency emerged as a shared value within the community. The role of moderators was also recognised, with their participation justified in ensuring that interactions remain respectful.

Keywords

online community, online participation, collective intelligence, digital inclusion, trust in social networks

"Aprendo Aqui o que Não Aprendo em Mais Lado Nenhum": Análise de uma Comunidade Online na Área da Saúde

Resumo

Este artigo procura analisar as dinâmicas que sustentam a comunicação de uma comunidade online na área da saúde focada nos cuidadores, intitulada "Vencer Autismo", que tinha como epicentro uma página do Facebook e um programa semanal em direto gerido por moderadores. A pesquisa privilegia a abordagem qualitativa: etnografia digital e entrevistas. O trabalho empírico decorreu durante nove meses, de setembro de 2022 a maio de 2023, tendo como fase determinante a etnografia digital realizada durante 10 semanas, a que se seguiram 10 entrevistas. A sucessiva cadeia de relações entre os elementos identificados permitiu descobrir que o conhecimento que ali se adquire é considerado raro pelos seus membros, se sustenta na experiência vivida, notando-se a valorização do aprender a fazer, da prova, a par do discurso irreverente, mas também que o contacto regular beneficia as relações e que o sentimento de inclusão atua como agregador. A confiança, outra das coordenadas estudadas, revela-se volátil — e ocorre num processo em construção — e depende de fatores mínimos, como o facto de os moderadores recusarem pronunciar-se sobre assuntos que não dominam. A transparência surge como o aspeto consensual. O papel dos moderadores é reconhecido e justificado também pela garantia da não civilidade das participações.

Palavras-chave
comunidade online, participação online, inteligência coletiva, inclusão online, confiança nas redes sociais

1. Introduction

Online communities have become a key part of everyday communication, influencing various aspects of daily life, from personal and family matters to professional and niche interests. Their growth has been significantly enhanced by the rise of social media platforms (SMPs), which enable instantaneous connections between individuals sharing common interests or goals.

It is possible to identify various types of online communities, each based on different platforms and serving distinct purposes and values. Several studies have explored the unique characteristics of specific communities (Xie et al., 2021), their benefits (Hwang & Foote, 2021; Weld et al., 2024), and their potential drawbacks (Weld et al., 2024). Some research also highlights the epistemological potential and innovative features of these communities, such as the creation of knowledge that goes beyond common sense or established scientific frameworks (Zaslow, 2012).

This research aims to explore the dynamics of an online health community created to support carers, with a focus on two key aspects: information acquisition and trust-building. Digital ethnography formed the primary methodological approach, from which six categories emerged and were further developed through interviews: "participation", "interactivity", "knowledge", "sharing", "credibility", and "trust".

The article is based on the premise that analysing an online community is a qualitative social research approach that offers insights into how people participate and interact digitally, sharing fragments of their lives and exchanging opinions to generate knowledge (Vilches et al., 2023).

An online community provides access to people's spontaneous and unfiltered behaviours, which are part of daily life and foster strong bonds between participants. These can be studied by analysing interactions, the intensity, and the quality of communication (Vilches et al., 2023), all while adhering to Goffman's (1974) view that people construct and reconstruct the course of interactions. As Kozinets (2020) emphasises, online communities are a unique social phenomenon where personal and intentional choices are made and materialised through connections formed at various levels.

Within health communities, the sub-theme of “carers” provided an opportunity to analyse the credibility of knowledge and the establishment of trust. The Facebook page of the Vencer Autismo (Overcoming Autism) community was selected for its diverse content in various formats because it was managed by the founders and for its weekly programme that allowed for live interaction. This Facebook page served as the community’s focal point, with its activities extending to a website, private WhatsApp groups addressing specific autism issues, live talks, and workshops.

This article is structured in six sections. Following the introduction, a literature review is provided on online communities, the evolving conceptions of such communities, and studies focused on health and carer-related communities. The third section describes the online community under study, while the fourth outlines the methodology and procedures used. Interviews were conducted to explore themes in greater depth. The fifth section presents the findings, and the sixth offers conclusions and suggestions for future research.

2. Online Communities

With the expansion of SMPs — marked by the launch of Facebook in 2004 — the development of online communities has flourished. These communities can take various forms, such as forums, social media pages, websites, blogs, or WhatsApp groups (Amado, 2014).

The growth of online communities has been enhanced by the performance of algorithms in SMPs. These algorithms determine what we see in an SMP by prioritising content shared by friends over other perspectives, helping us find information with a sense of familiarity (Gillespie, 2014). On the positive side, algorithms offer a privileged means of gaining knowledge, facilitate participation in social and political discourse, and help us connect with our audiences. According to Gillespie (2014), algorithms have become essential to knowledge acquisition, though they may also obscure influential interests in the cognitive process.

The GlobalWebIndex platform (Mander & Koch, 2020) reports that online communities have become an increasingly trusted source of information, with this trust growing among young digital natives. The *Era of We* report highlights that they place greater trust in news shared within a community context than in traditional media spaces.

Online communities have been studied across various scientific fields. A search on the Perish platform (conducted in May 2024), which retrieves articles from Scopus, Web of Science, and Google Scholar in chronological order while identifying keywords and authors, revealed that the first 20 results fall under the categories of “health”, “IT”, “education”, “psychology”, “management”, and “marketing”. Thus, this research incorporates interdisciplinary contributions that align with its objectives.

Online communities are increasingly diverse in their objectives and motivations. What unites them is their ability to help participants find practical solutions (Liu et al., 2020). In the Vencer Autismo community, we observed relational dynamics and, above all, the benefits for users in terms of information, knowledge, and trust.

Rheingold (1993), a pioneer in conceptualising and analysing so-called "virtual" communities, studied the WELL community and argued that an online community possesses a coherent identity shaped by several key characteristics: people meeting in an online environment, engaging in public discussions over a sustained period, and sharing emotions. He viewed connectivity as a space that enables emotional exchange and debate with the potential to generate knowledge.

The history of online communities entered a new phase with the introduction of the concept of "communities of practice" and its expansion into the digital sphere as online communities of practice. Coined by Wenger (1998), the term "communities of practice" emphasises the importance of interaction and experience-sharing in fostering a conducive environment for learning from others, based on the premise that knowledge emerges through sharing. This concept has been particularly influential in professional and educational contexts.

Preece (2001) highlighted the importance of online communities for their members, as they enable interaction and information exchange, with their success hinging on socialisation and usability. Sociability encompasses objectives and policies, while usability includes dialogue, support, information, and accessibility. Subsequent studies — such as Ridings and Gefen (2004), Hwang and Foote (2021), and Xie et al. (2021), among others reviewed in the literature — have identified purpose, people, policies, dialogue, support, and ease of navigation as key factors in member satisfaction. According to Ridings and Gefen (2004), the primary motivations for participating in online communities include exchanging information, seeking support, building friendships, and engaging in recreational activities.

Online communities, whether more or less specialised, can be seen as spaces for sharing information. Lévy (2000) argues that they create the conditions for the emergence of "collective intelligence", which he defines as a body of knowledge shared through memory and based on mutual recognition, leading to learning. The community is crucial because it serves as a site of continuous negotiation. Collective intelligence thus emerges as a powerful strategy for problem-solving in the age of internet proliferation (Lévy, 2000). Alongside Lévy, Castells (2002), Tapscott and Williams (2006), Surowiecki (2014), and Malone and Bernstein (2022) have also explored the concept, incorporating this interpretative framework.

Kozinets (2020) argued that the complex world of online communities not only reflects lived experiences but also becomes a unique social phenomenon. Their complexity arises from the fact that they are chosen by individuals, sometimes temporarily and to varying degrees. These communities are "transnational and local" spaces (Rokka & Moisander, 2009). Echoing Bauman (2000), Kozinets advocates for the liquid, unstable, and unpredictable nature of these communities. Researchers highlighting the potential for knowledge-building include authors like Benkler (2006), who believes that sharing can provide autonomy and freedom, and Gorbis (2013), who suggests that online communities can incorporate structural axes for the future.

2.1. The Interactive Consumer

To frame what is considered structural in online communities, Bruns (2014) highlights the concept of "produsage", which suggests that the consumer is also a producer — a "prosumer". This idea, introduced by Toffler (1980), predicted that technological advancements would lower the barriers between consumer and producer, placing greater value on participation and collaboration. Bruns (2014) argues that consumers are not simply passive; they are also producers of information. Their role is flexible, allowing them to contribute to and modify content, constantly adapting within a collaborative model.

Bruns' (2014) assumption forms the foundation of his concept of the "online community". He distinguishes an online community from an online group, along with other audience categories, by considering the level of interaction and shared values. In a group, the connection is often centred around a specific topic, with weak cohesion and minimal participation demands. In contrast, the online community is characterised by a core group of highly engaged users who share strong values, practices, and knowledge. Bruns (2014) also identifies additional layers or cores of participants who, as they become more distant, show less commitment. Thus, the community adopts a more complex structure, comprising both a centre and a periphery. The online community is seen as another element of the fragmented public sphere, made up of a network of publics, highlighting the advantage of representing a group united by shared interests with its own rules and practices.

Bruns and Bahnisch (2009) analysed the dynamics of online communities, explaining that the structure based on levels of participation makes it easier for less committed individuals to contribute. Another key characteristic is the equal opportunity for participation, irrespective of ability, allowing each user to make a meaningful contribution. In terms of emotions, they highlight how the shared generation of content fosters a sense of ownership among participants. The authors recommend that website and RSO managers respect these dynamics of online communities. They suggest, among other things, being as open as possible to new users, encouraging the community to differentiate between good and bad content, and, as the community defines its values and objectives, promoting the emergence of leaders. They also stress that communities evolve, and it is important to support and encourage these changes.

Regarding the concept of "consumer", Couldry (2004) argues that the new media ecosystem has blurred the distinction between consumer and citizen. The productive consumer must be understood within the broader framework of public space, connection, and participation. In the context of new media, participation takes on new dimensions. Carpentier (2020) distinguishes three categories: "access", "interaction", and "participation" itself. Access refers to the possibility of being heard, representing the opportunities created for communication to take place. While readers may be given a voice, they do not influence what is produced or how. The second level, interaction, involves the articulation of socio-communicative relationships within the media sphere, enabling content co-production in groups or communities. However, the final decision remains in the hands of media organisations. Participation, in contrast, implies that citizens are not only interlocutors and co-producers but also co-decision makers and creators. This new consumer also navigates an economy in which attention has become both scarce and fluid. Individuals consume and interact across platforms, influenced by emerging technologies and algorithmic changes (Myllylahti, 2019). Additionally, the spaces where media engagement occurs must be considered. As the traditional division of time between work, home, and leisure becomes less rigid, media consumption increasingly takes place in hybrid time (Kowalski & Jung, 2021).

A study by Hwang and Foote (2021) on participation in Reddit communities found that engagement in smaller communities offers additional benefits, including increased knowledge, trust, and support. Trust, in turn, is influenced by familiarity with other community members and shared interests, as evidenced in an analysis of participation in two hyperlocal, community-produced newspapers (Gonçalves et al., 2024).

Small communities are often centred around highly specific topics and a singular purpose. Even if members engage at varying levels, the community retains a distinctive character that enhances the potential for interaction. In these niche spaces, expectations are high, as participants seek high-quality information, often associated with the presence of experts. Consequently, these communities are also perceived as more effective (Hwang & Foote, 2021).

2.2. Knowledge and Trust

In the health domain, access to information and the establishment of trust are crucial, highlighting the need to understand motivations, knowledge acquisition processes, and the perceived added value of participation. To explore these aspects, we draw on studies related to health communities, particularly those focusing on carers. Two case studies from Portugal (Guilherme, 2013; Pestana, 2010) found that the primary motivation for joining a health-related community was obtaining and exchanging information. One of the key benefits identified was the opportunity to ask specific questions to strangers in a dedicated space (Pestana, 2010). Similarly, Ridings et al. (2022) emphasise that virtual communities provide access to specialised information. This factor fosters a sense of closeness among members, particularly in health-related discussions, ultimately contributing to the development of trust.

A study by Lupton (2016) on a community focused on pregnancy and motherhood highlights the significance of detailed information alongside other key aspects such as immediacy, regularity, entertainment, personalisation, practicality, professionalism, reassurance, impartiality, and opportunities for user participation and content creation. Similarly, an analysis of a community of mothers with children with sensory disorders concludes that collaborative communication fosters a distinct form of knowledge — one that is neither purely medical nor simple advice. Instead, it enables the emergence of a new epistemology grounded in the sharing of lived experiences (Zaslow, 2012).

In addition to the advantage of specialised and distinctive knowledge, some studies have highlighted the role of emotional support. A survey of an amyotrophic lateral sclerosis community (Guilherme, 2013) found that emotional support often takes precedence over informational motivation during participation, even though community members may not consciously recognise this. This conclusion aligns with research on knowledge sharing in online mothers' communities (Xie et al., 2021), which found that emotional support is sometimes more essential than information. Xie et al.'s (2021) review of studies on mothers' communities further concludes that mothers primarily value experience-based accounts and tend to accept what is most popular within the community.

With regard to credibility, several studies highlight key factors that contribute to its establishment in online communities, including the reliability of information sources, presentation style, and supporting evidence (Zhao et al., 2024). Another perspective emphasises the importance of perceived usefulness. Higher-quality information, combined with consumer comprehension, enhances credibility. As a result, consumers rely not only on indicators of the source's expertise and the digital "word of mouth" system but also on their perception of the information's usefulness. Perceived usefulness significantly influences information adoption and serves as a key motivator for acceptance (Gerashi et al., 2023).

One of the key factors in consolidating communities is the sense of trust, which develops through relationships with others and the ability to include them in a shared frame of reference (Matos-Silva et al., 2012). Trust becomes particularly significant when members recognise organisations and professionals as credible sources (Zhao et al., 2024). Research also suggests that the presence of moderators can play a crucial role in fostering trust, while humour can serve as a tool for negotiating it (Lovatt et al., 2017). Additionally, the *Digital News Report Portugal* (Cardoso et al., 2024) highlights transparency as the most important factor for trust in news media, with 79% of Portuguese respondents identifying it as essential.

3. Vencer Autismo Community

The Vencer Autismo community was founded in 2010 by a couple with an autistic daughter. Associated with a non-governmental organisation, it operated through a website and a Facebook page, which served as platforms for hosting talks and workshops. This research focused on the activity of its Facebook page, which had 240,000 followers in 2022.

At the start of this analysis, the community regularly broadcasted the *Café Vencer* (Overcoming Café) programme, providing an opportunity to observe live interactions among members. The live programme was moderated by the community manager, who holds a degree in Business Management, alongside professionals in education and psychology.

The website's managers were contacted and informed about the ongoing research, particularly the non-participant observation, and were open to collaborating. One edition of the weekly programme publicised the study and encouraged participation. Confidentiality and the coding of all collected information were ensured at every stage of the research to prevent any form of identification and to safeguard personal data. All participants remained anonymous, with their names never disclosed — only numerical identifiers were used. It is worth noting that the group was open access at the time, allowing anyone to join without providing any personal information.

The page's popularity was evident not only from its number of followers but also from external recognition. In 2022, its founder was invited by a member of the European Parliament to visit the European Parliament and share their experience. By mid-2023, the community had adopted a parallel subscription-based format.

The Portuguese Association for Autism Developmental Disorders (https://www.appda-lisboa.org.pt/) describes autism as a developmental disorder of the nervous system, characterised by a wide range of symptoms that are often not immediately identified in childhood. Key indicators include deficits in social and emotional reciprocity, limited sharing of interests, emotions, and affections, as well as difficulties in understanding and using language. In other words, autism involves challenges in communication and social interaction, which, according to the association, can vary in severity. Parental involvement is crucial in navigating diagnoses and accessing therapies through the National Health Service, though interviewees noted that available support may be insufficient.

According to one of the interviewees, a carer of an autistic child, institutional and educational support is scarce.

> Our son was referred to the National Health Service and began receiving speech or occupational therapy. But it is far from sufficient. The health services and the state provide too little. That is why these groups are so active. (Interviewee 3)

This analysis focuses on communication dynamics and does not aim to explore the medical dimension or institutional support.

4. Methodology

This research adopted a qualitative methodology, combining digital ethnography and interviews. Initially, all forms of communication on the Vencer Autismo Facebook page were monitored for nine months, from September 2022 to May 2023. This phase served as an exploratory process of documentation, followed by a more detailed application of digital ethnography over 10 weeks. The analysis was concluded when it was determined that the collected data had reached saturation (Burrell, 2017). After this stage, 10 semi-structured interviews were conducted — two with moderators and eight with community members — allowing us to validate findings and explore private aspects in greater depth.

We observed and documented all communication formats, including content and interactions. The initial phase of the research aimed to identify the most strategically relevant "fieldwork" for analysis, following one of the steps proposed by Burrell (2017).

Over 10 weeks, from October 1 to December 8, we conducted a detailed data collection through non-participant observation of the dynamics. The guiding principle of this work was an openness to the nuances of what is referred to as "digital culture", particularly the creative commons and other modes of digital sharing and collaboration (Pink et al., 2015). This analysis focused on an open-access Facebook page, which may have influenced participants to maintain a certain level of decorum in their interactions.

During the exploratory phase, special attention was given to key figures, online traces — textual, graphic, and other audiovisual elements — interactions, and consociality, that is, what is shared (Kozinets, 2020). The data collection process considered emerging languages and symbols, routines and rituals, storytelling approaches, the sharing of beliefs, values, and power dynamics, as well as connections to other platforms, online initiatives, popular videos, and announcements.

When designing the interviews, we first evaluated which model would be most suitable for exploring topics that are both broad and subjective. Following Braun and Clarke (2006) and Ferreira (2014), we defined two methodological paths: prioritising thematic analysis (Braun & Clarke, 2006) and adopting the comprehensive interview approach (Ferreira, 2014).

A total of 10 interviews were conducted via Zoom, the first two with the main moderators. The remaining interviewees were invited through the Facebook page and the weekly programme. Parents — particularly mothers — grandparents, and teachers of autistic pupils agreed to participate. Their professional backgrounds include teaching, technical assistance, administration, and engineering (Table 1). All interviewees were informed about the confidentiality of their responses, and informed consent was obtained.

INTERVIEWEES	AGE	OCCUPATION	REGION	RELATIONSHIP
Interviewee 1	50 years old	Management	North	Father
Interviewee 2	33 years old	Communication	North	Acquaintance
Interviewee 3	43 years old	Engineering	North	Father
Interviewee 4	44 years old	Technical Assistant	Centre	Mother
Interviewee 5	38 years old	Engineering	Centre	Mother
Interviewee 6	54 years old	Teaching	Madeira	Acquaintance
Interviewee 7	58 years old	Technical assistance	Centre	Grandmother
Interviewee 8	42 years old	Technical Assistant	Lisbon	Mother
Interviewee 9	34 years old	Administration	Centre	Nephew
Interviewee 10	39 years old	Teaching	Algarve	Acquaintance

Table 1. *Description of the Interviewees*

The main themes of the interviews emerged from digital ethnography. The questions were structured around six dimensions of analysis — "participation", "interactivity", "knowledge acquisition", "sharing", "credibility", and "trust" — which were grouped in pairs. During the conversation, the approach was to allow the interviewee time to feel comfortable and to assess their connection to the topics.

5. Findings

5.1. Monitoring the Vencer Autismo Facebook Page

The initial analysis of the page highlighted the frequent use of blue heart emojis and prayer symbols, as well as a preference for sharing personal experiences through comments. Exchanges between members also revealed that some parents had created separate WhatsApp groups to address specific issues, aiming to facilitate urgent responses. The moderators' role in leading the weekly Café Vencer broadcast stood out, particularly their empathy towards members. Notably, newcomers to the programme were generally well-received.

From October 1 to December 8, 2022, the page's activity was monitored using an editorial calendar, broken down by the number of posts made each week, the breakdown of production, and post categories. It was concluded that there was almost daily posting (Table 2). In other words, the page user obtained information at a regular pace. The days with the highest number of posts were Wednesday, when the *Café Vencer* event takes place, followed by Thursday and Friday. Sunday had the fewest posts. In the breakdown by post category, the most common was the announcement of activities (Table 3 and Figure 1), followed by messages from the team running the page, especially the founder. Their narratives are based on personal testimonies and feature storytelling.

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
0	1	1	0	3	1	0
0	1	1	3	2	2	0
0	1	2	2	3	3	0
0	2	1	1	2	2	0
0	1	1	2	2	2	0
0	1	1	2	2	1	1
2	3	0	3	1	1	0
0	1	3	2	1	2	0
1	1	0	2	0	1	1
0	1	1	2	1	0	0

Table 2. *Number of posts*

10 weeks	
Number of posts	Categories
80	Internal activity announcements: *Café Vencer*, free and paid lectures, workshops
	External announcements
	Weekly programmes
	Explanations about autism/graphics
	Videos featuring the team
	Other: funny videos, surveys, and photo shoots

Table 3. *Breakdown of production*

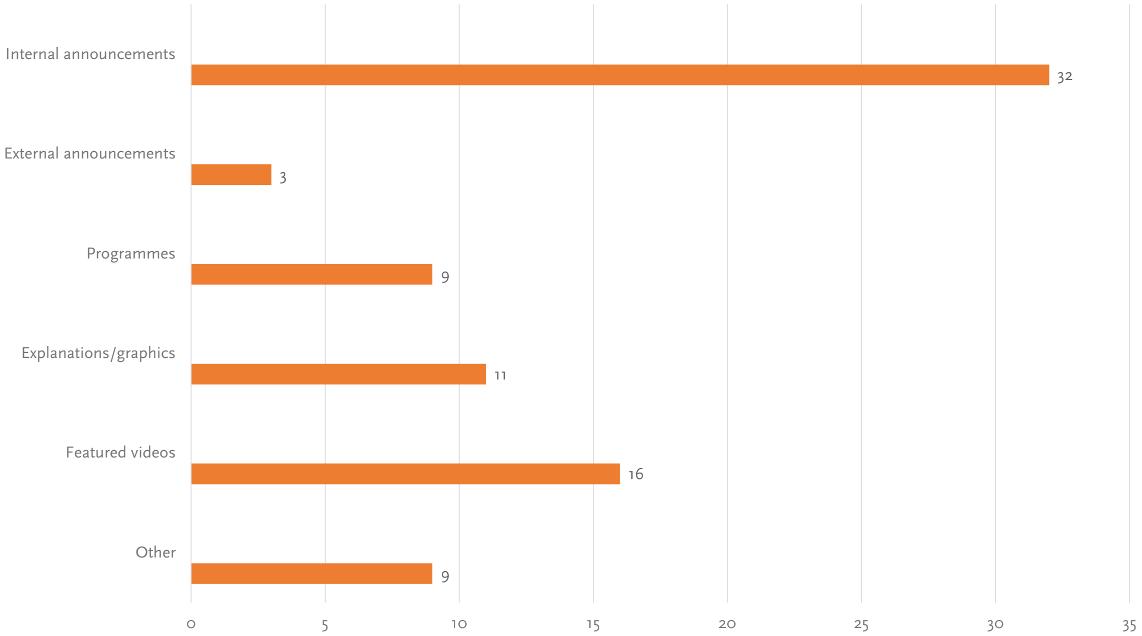

Figure 1. *Breakdown of categories over 10 weeks*

The communication on the Vencer Autismo website also employed straightforward, informative narratives (Figure 2), frequently addressing autism-related issues in a question-and-answer format. According to the interviews, design professionals were hired for this purpose. As a result, there was an effort to simplify the message while also making it engaging and light-hearted, thereby reducing any negative connotations associated with the topic.

Café Vencer #002

Q.

Como estimular a fala?

A.

Existem várias fases no desenvolvimento da fala.

Devemos perceber em que fase da comunicação a nossa criança se encontra.

É importante não antecipar aquilo que a nossa criança quer e dar-lhe espaço para que tente comunicar connosco.

Figure 2. *Example of a graphic announcement*

Source. Retrieved from *Sabemos que algumas crianças podem ter atraso na fala e que muitas desenvolvem esta competência mais tarde do que a média* [Photograph], by Vencer Autismo [@associacaovencerautismo], 2022, Facebook. (https://www.facebook.com/associacaovencerautismo/posts/pfbid037YznrAogaPcHoPTMJ2qpXGoKzNFh2YkhkvGp8Aevj42UxM99D363pmcwGwd4Zn5fl)

Note. Translation: "Q. How to stimulate speech? A. Speech development progresses in several stages. We need to assess which stage of communication your child is currently at. It is important not to anticipate what our child wants and instead allow them the space to attempt communication with us".

5.2. ANALYSIS OF THE *CAFÉ VENCER* PROGRAMME

Simultaneously, a detailed analysis was conducted of 10 editions of the *Café Vencer* programme, which aired between October 12, 2022 and January 4, 2023. The programme addressed questions submitted throughout the week, as well as those that emerged during the live broadcast (Figure 3).

Figure 3. *Stages of the programme*

The moderators and other participants provided the answers. The moderators were identified as "Moderator 1" and subsequent numbers, while participants were also assigned a numerical designation, such as "Participant 1". The moderators rotated throughout the sessions, though they always worked in pairs. The most regular technician, who holds a degree in Educational Sciences, was occasionally paired with a psychologist. The founder of the website and other professionals associated with the organisation also participated. The programme starts with a welcome note addressing the participants by name, and the initial minutes are used to encourage conversation. If someone shares their location, others often mimic this behaviour, and it becomes apparent that participants come from various regions of the country, ranging from Covilhã to Porto, as well as from abroad, including England and Switzerland. A rule of the programme is that no questions go unanswered. During the survey, only one question remained unanswered.

Concerning the moderators' positions, they were careful not to comment on controversial topics, such as medication and the use of cannabis. They refrained from offering answers in scientific areas outside their expertise: "I have no knowledge, no studies. I also don't have the experiences of others to share on this subject" (Moderator 1). A notable example occurred when a mother claimed that coffee helped calm her son down, which sparked a debate within the group. Some parents agreed, asserting a cause-and-effect relationship, while others disagreed. During the broadcast, the moderators openly admitted that they didn't know the correct answer (Moderator 1 and Moderator 2).

The relationship between likes and comments was also analysed, revealing that those who engaged with a like were more likely to participate in the conversations, indicating a higher level of involvement (Figure 4).

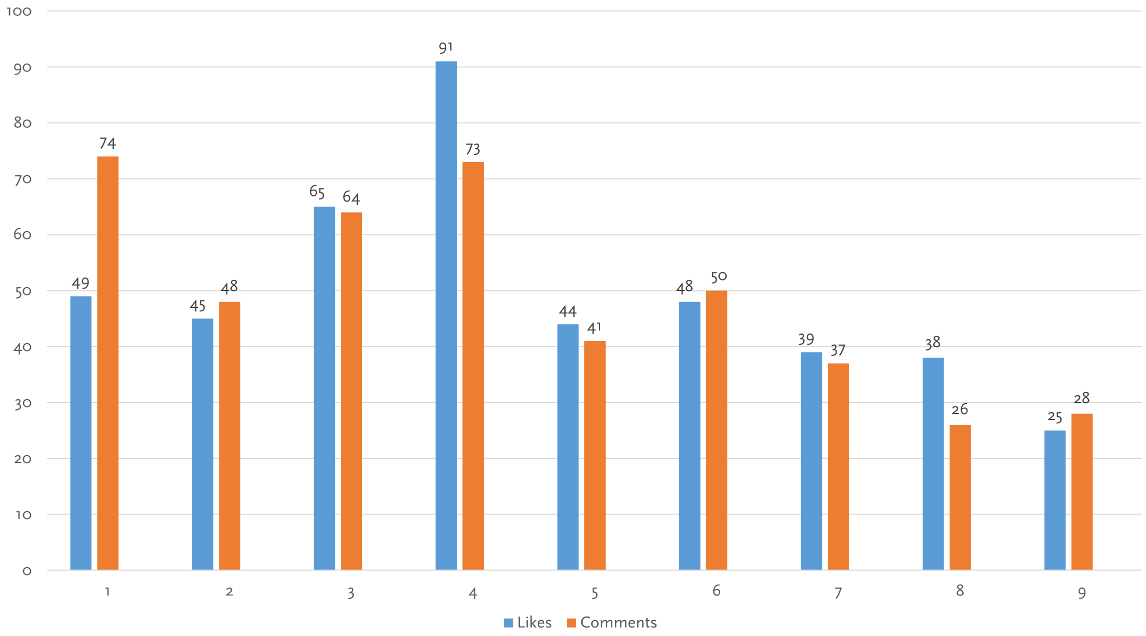

Figure 4. *Participant reactions*

Participants' involvement in the community was clearly visible through their regular comments on various posts, demonstrating the active participation of many members in different ways. As one of the moderators mentioned: "X never misses a *Café* [*Vencer*]" (Moderator 1).

From the content of the conversations, it is evident that some participants had previously attended lectures and participated in workshops, reflecting a connection to in-person events. The comments were almost always accompanied by emojis, with the most frequently used symbols being the blue heart, the faith symbol, and the gratitude symbol, which added an emotional layer to the verbal expressions.

In terms of content, the testimonies shared by the moderators about their experiences generated the most comments, indicating that they play a key role in driving communication. The programme that attracted the most attention was the one featuring the founder's daughter, a young autistic girl who, despite her condition, successfully entered university, serving as an inspiring example of resilience and achievement.

The main focus of communication centred on practical strategies for addressing everyday challenges, such as getting a child to take a bath. Regular participants contributed additional information to that provided by the moderators, creating a second layer of insight. As Bruns (2014) proposed, different levels of participation can be identified. The topic of aggression sparked strong engagement, with the discussion of dramatic themes generating intense participation that reflected identification and empathy: "my son is like that too. I would try to keep him away from that colleague" (Participant 1).

The posts made by moderators who have lived through the challenges of autism generate the highest levels of participation, particularly when they share personal experiences.

This reaction aligns with the concept proposed by philosopher Merleau-Ponty (1976) in *Phénoménologie de la Perception* (Phenomenology of Perception). The sharing of concrete cases and the subsequent problem-solving were other key features of the broadcasts. Lastly, it is worth noting the expression of gratitude, as one participant remarked: "they helped me a lot, they said things I hadn't thought of, so good! I even feel lighter and more energised. Very, very grateful" (Participant 2).

5.3. Analysing the Interviews

Regarding the main reasons for participating in this community, replies varied from the need for support and the search for knowledge to the immediate response for problem-solving. The first two reasons had already been highlighted in a study on the amyotrophic lateral sclerosis community (Guilherme, 2013), which concluded that, initially, participants' motivation is to seek knowledge. However, over time, emotional support becomes more significant and even outweighs the initial drive for information. Analysing the interviews, however, allowed us to expand the "support" dimension. For the participants, companionship, acceptance, understanding, a sense of belonging, and respect were crucial: "socialising with other parents was very important; we are not alone. We feel that nobody understands us, and there is a common ground for understanding" (Interviewee 3), and "often, these parents have nobody to talk to about these problems. They feel alone" (Interviewee 6).

Some carers have distanced themselves from friends and family due to their children's behaviour, which is often perceived as socially unacceptable. They speak with pain about the lack of understanding from their family and friends. It is precisely this understanding and sense of inclusion that they find within the community: "for parents who find it difficult to keep friends who are unwilling to engage with their autistic child or those who have self-censored, it was reassuring to feel understood" (Interviewee 8).

At the same time, they mentioned having learned strategies for dealing with prejudice: "this participation has helped me fight the [autism] stigma" (Interviewee 4). One of the interviewees also valued the respect he felt: "having people there who respect autism is the most important thing I take away from this participation" (Interviewee 5).

The positive tone of the programme reflects a perspective on autism that deserves praise. Several parents mentioned that the programme has given them hope and a sense of encouragement in the face of their difficult situation: "people feel lost, but then we offer ways to approach things, and hope begins to emerge" (Interviewee 3); "they talk about hope at the end of the tunnel" (Interviewee 4).

Regarding interaction, most members acknowledge that they listen more than they speak. As Carpentier (2020) points out, participation can occur at different levels, ranging from simple access to reaction and active participation with impact. However, they feel compelled to intervene whenever they identify with one testimony and believe they can offer help. Another aspect they value is the quick response to problems, as in the context of autism, a question can arise at any time.

When analysing the "knowledge" category, the way it is communicated stands out, with participants praising the use of simple, concrete language and useful information drawn from experience and focused on solutions: "we're talking about simple, practical knowledge. It's not theoretical. The advantage is that it presents a range of solutions for our child" (Interviewee 9); "it's very important to hear 'I've been there'" (Interviewee 8); "I've been there, done this and that, and it worked" (Interviewee 3).

The fact that some suggestions differ from the guidance provided by conventional sources — such as doctors and therapists — appeals to certain community members. The alternative approach is seen as knowledge beyond the obvious: "it's more than complementary information. Everything I've learned and been able to put into practice has come from Vencer Autismo. There is so much sharing among parents that the information is invaluable" (Interviewee 3).

> We learned how to stay calm during a tantrum. I learned that it was important for the child to accept me, that they needed to build a relationship with me, and that this required time. Also, the solutions might not be conventional. (Interviewee 6)

"There doesn't have to be a politically correct approach to dealing with these issues" (Interviewee 6).

Further to the topic of knowledge, the interviewees primarily highlight the practical aspects of the methods, emphasising that the knowledge gained is often very specific and rare: "we learn from the experience of others, but in a very subtle way, from small things" (Interviewee 10).

> I found knowledge there that I hadn't seen anywhere else. It's useful knowledge, teaching you how to do things. This kind of knowledge comes from group meetings and the sharing of experiences. Nowadays, the habit of gathering has been lost, but these meetings can be incredibly productive in terms of learning. (Interviewee 6)

He also adds that he appreciates the freedom parents have when it comes to making choices: "it's a space for parents to reflect and apply the teachings in their own way. It provides a sense of comfort" (Interviewee 6).

The issue of credibility, along with trust in the information, seems to be grounded in the founder's personal experience and the practical application of the teachings. However, trust was the aspect that interviewees reflected on the most. Notably, they highlighted initial scepticism and the perception of the process as ongoing: "I began to trust when exchanging information with other parents started making sense. And then, of course, when we confirmed the results. The results give you confidence" (Interviewee 8); "there was initial mistrust. We [with her husband] analysed it. I also take part in two other parent' groups" (Interviewee 5).

Some respondents appreciated that the moderators acknowledged not knowing everything. They also highlighted the authenticity and transparency of the information, particularly the moderators’ clarity regarding which lectures and workshops required payment. “the moderators don’t give opinions on medication. They don’t try to influence. They don’t speak with absolute certainty. Their suggestions may or may not work. They convey authenticity effectively” (Interviewee 4).

> First, I had a look and analysed the page. I realised they project authenticity. They make themselves available to help and respond, which is reassuring because they understand what we’re feeling. Support, help, clarification, and guidance contribute to trust. (Interviewee 10)

In the final part of the analysis, the results of the digital ethnography were combined with the key insights from the interviews (Table 4), leading to the conclusion that the greatest added value for this community lies in knowledge based on detailed and concrete procedures derived from lived experience — knowledge not readily available elsewhere. However, acquiring this knowledge cannot be separated from psychological and emotional dimensions, such as support and a sense of inclusion.

	Netnography	Interviews
Participation	Support and help	Counteracting the isolation of dealing with this issue
	Personalised greetings	Always welcomed
	Reporting their experiences	Experiences paired with strategies
	Everyday problems	Immediate response
		Helps deal with prejudice
		Listening more than participating
		Lively approach to autism
Interactivity	Clarify doubts	When it impacts the individuals
	Validating testimonies	Moderators’ friendliness and empathy
	They ask what topics individuals want to see addressed	Gaining skills
Knowledge	Simple language	Feasible, accessible solutions
	Useful information	Teaching how to do
	Identification with the problem	Unconventional answers
	Very special episodes	Solutions for concrete problems
		Confirming results

Sharing	Emotional situation	Surprise information
	Teaching how to do	Can be done through other channels (e.g. WhatsApp)
	Led by autistic people	Replicating leaders
Trust	Limited questioning	Initial mistrust. Trust as a process under construction
	Personal experience of the founders	Accounts of lived experience and overcoming with proof
	Behaviour of the moderators	They do not comment on non-scientific topics
	Controversial topics viewed with caution	Moderators do not comment on topics relating to other treatments
		They do not judge anyone
		Uncivilised discourse is gently excluded
	Combination with lectures and workshops	Quick explanation of prices
Credibility	Clear information	Easy confirmation from other sources

Table 4. *Relationship between digital ethnography and interviews*

This research has provided clues for other themes to explore in the future. One of them concerns how the moderators dealt with "inappropriate speech". Initially, the moderators responded by explaining that the space was not suitable for such comments. If the individual insisted, the moderators would downplay the participation.

6. Conclusion

This study suggests that lived experience serves as a "glue" for the communication established within this online health community led by carers. This aspect is crucial in two respects: first, lived experience forms the foundation of the community's appeal, shared knowledge, and collective understanding; second, it provides the basis for the unique information that is discovered and developed within the group. For community members, one of the key benefits of participation is access to a type of knowledge they cannot find in other sources, such as medical or psychological information. This knowledge is practical, detailed, concrete, and solution-oriented, offering quick responses. It is also delivered in clear, easily understandable language and with an engaging approach, which fosters a sense of hope.

This research concludes that the cognitive aspect cannot be separated from the psychological and emotional dimensions, particularly those related to support and acceptance by others. These two factors are evident in the interview responses. In addition to the emotional support — stemming from the sense of identification with shared challenges — and the mitigation of loneliness, the element of inclusion plays a key role. Peer acceptance, often described in an intimate tone during the interviews, underscores the significance of these online communities for their members. Within these online spaces, community members are free from stigma and prejudice and are able to navigate the socialisation challenges posed by their children's behaviour. Whether through support or inclusion, emotion and knowledge are interwoven, working in tandem.

The engaging activity on this page, particularly through consistent and well-timed posts, captures and maintains the attention of community members, acting as a unifying force. Constant accessibility, highlighted by the moderators' responsiveness, is deemed essential for the smooth operation of the online community. The use of straightforward language, visually clear graphic materials, and humorous narratives enhance communication effectiveness.

Building trust emerges as a flexible, adaptable process that relies on the convergence of several factors. It is tested with every new response. When in doubt, members turn to alternative methods to verify the information. For instance, community members appreciate that the moderators openly acknowledge when they lack expertise on a certain topic, prioritising transparency and providing swift explanations to alleviate uncertainties and prevent mistrust.

It is also worth noting some subtle aspects that members perceive as added value, such as the sense of freedom in choosing strategies for working with autistic family members or students and their preference for applying knowledge "outside the box". This approach gives them the feeling of transcending the obvious and conventional.

This analysis has opened up a potential area for future research, particularly regarding the role of moderators, the models to adopt in order to avoid uncivilised discourse, and the significance of the sense of inclusion within specific communities.

Translation: Anabela Delgado

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