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MESTRADO EM PSICOLOGIA
PSICOLOGIA CLÍNICA E DA SAÚDE

Online Community-Based Coping Strategies Among Individuals Affected by Hereditary Diseases: An Exploratory Analysis

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2025

Index

Abstract

This study investigated the lived experiences of individuals who have either received a “carrier” result for a hereditary disease through predictive genetic testing or are confronted with the prospect of undergoing such testing. In navigating the complexities and emotional challenges associated with the testing process and resultant disclosure, participants often sought information, guidance, and support through online platforms to aid decision-making and emotional adjustment. This research used Reddit as a source to understand the coping strategies that these individuals use in online spaces.

To analyse these interactions, we conducted a thematic analysis of the posts made in various hereditary diseases subreddits. Both posts and replies have been used for this analysis to study the interactions between users. These interactions allow the users to talk about frightening, sensitive, embarrassing and/or taboo experiences which potentially reduce the psychological impact of their experiences facilitating a sense of individual and collective empowerment in a context where people can feel powerless.

By building a cohesive and supportive community, coping is not only possible at an individual level but also as a communal effort. The collective exchange of experiences and the joint exploration of potential solutions to the challenges posed by illness exemplify communal coping, where in individuals appraise the illness as a shared concern and collaborate to address its demands, thereby fostering mutual support and group resilience. This study shows the efficacy of online community-based interventions in addressing the multifaceted challenges associated with hereditary diseases. These interventions leverage the online community as a critical psychosocial resource, functioning as a platform for the provision of emotional support, a forum for articulating personal health concerns, and a network through which individuals affected by similar genetic conditions can seek and offer reciprocal support. In these virtual environments, members engage in mutual aid, sharing experiential knowledge and coping strategies that promote psychological resilience and enhance disease management. Such platforms not only facilitate the dissemination of condition-specific information but also engender a sense of communal belonging, mitigating patient isolation and fostering empowerment through collective understanding and solidarity.

Introduction

Advances in genetic testing have improved the speed and accuracy of rare disease diagnosis (Maron et al,2023). Genetic testing is a powerful tool that shortens the diagnosis process and helps to alleviate some of the financial and psychological burdens associated with undiagnosed conditions (Wojcik et al.2024). While the technological aspects of genetic testing have advanced, less is known about the psychosocial factors that influences the individual decision to pursue testing.

Individuals will seek strategies to reduce the negative consequences associated with a hereditary disease. Lazarus & Folkman (1984), define coping as mechanisms used by the individual to face a stressful situation. These mechanisms usually focused more on the individual personal capabilities to address the said difficulties. Coping strategies can be distinguished between problem- focused and emotional-focused strategies (Lazarus & Folkman, 1984). Problem focused strategies involve confronting the situation, seeking social support and making concrete plans. Emotion-focused strategies involve control of one´s feelings, reappraisal of self, escape/avoidance, and distancing. Lazarus (1999) suggest that problem-focused strategies are generally more effective than emotion-focused strategies. However, he also notes that the particular context will determine to a large degree the success of a given strategy. The critical points of decision taking in case of hereditary disease are the pre-test and the post-test. For the ones that are asymptomatic the decision of taking the genetic testing can be challenging since the knowledge that come with the testing, especially if it's an unfavourable result, will bring life changes that can be anxiety inducing (Rolland & Williams,2005). For the ones that are already showing symptoms genetic testing can give answers or aggravate the anxiety depending on the disease and the available treatment options or lack of them. To find more information about the illness, people may procure the internet.

The availability of health information on the web has increased dramatically over the past decade. A study revealed that, currently, 55% of health care information seekers are relying more on the internet and web-based sources for their health-related information than 8 years ago (Shandwick,2018). Online support groups offer an important aid in spreading the information resources and patients can also benefit from emotional and community support (Stanarević & Katavić, 2019). Individuals that use online communities report the advantages of a 24-hour availability of information and support

from others who may be far away. Even if the patient has a strong network of support from family and friends, individuals may benefit from having an outlet of people who can relate to what they are going through on a personal level. Traditional face-to-face groups can offer this support, but issues such as transportation, distance, privacy and time restrictions typically reduce participation and attendance.

Two major reasons that people use the internet for health-related concerns merge from reviews: first, to find biomedical information, and second to interact with others who have similar conditions for the purpose of sharing experiences and emotional support. Online groups usually provide some combination of both information and emotional support (Ashtari, & Taylor, 2022). Online groups also provide peer support, peer support can be defined as the help and support that people with lived experience of a hereditary disease can give to one another. These groups are usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life-disrupting problem, and bringing about social and/or personal change. Peer support can instil hope, improve engagement, quality of life, self-confidence and integrity (Shalaby & Agyapong, 2020).

The objective of this study is to investigate the coping mechanisms and adaptive strategies employed by individuals within online communities, examine the nature of their interpersonal interactions, and elucidate the emergent coping responses developed through such exchanges. This study seeks to generate insight into participants' lived experiences and subjective perspectives, thereby advancing theoretical understanding of psychosocial adaptation and resilience in digital collective environments. By analysing the stories shared spontaneously within online communities, it's possible to provide an authentic glimpse into the past and ongoing experiences of coping with a rare disease that interviews and surveys are hard-pressed to match (Han & Belcher, 2001).

Methods

This study uses a qualitative approach to analyse coping mechanisms used of people that are carriers of the gene alteration associated with hereditary diseases.

The sample data was extracted from people´s Reddit (https://www.reddit.com) posts, a social media and forum-style website were users have the opportunity to express their views in a diverse assembly of topics while maintaining their anonymity. Reddit is currently the largest and most influential online forum in the United States. In Europe the number of Reddit users in 2025 was around 133 million (World Population Review, 2025).

Online forums provide the researcher a first-hand account and narratives of the people that share their personal narratives while trying to cope with their unfavourable genetic test results (test results that indicate that the individual has a hereditary illness), and of those that are struggling with the anxiety and indecision of taking a genetic test. Reddit also has the advantage of being accessible to the general public without any encryption and is also anonymous, thus when collecting data from Reddit there are minimal ethical concerns.

A qualitative approach was chosen since it allows the exploration of the distinctive aspects of each case and the in-depth information provided in each person testimonial, this contributes to a comprehensive understanding on how individuals use different strategies to cope with a positive result in a predictive genetic test. A qualitative approach offers the opportunity to construct a comprehensive narrative regarding individual´s inner experiences with specific contexts, as well as uncovering aspects that may not have been considered previously (Banister, Peter, et al, 2011.p.7).

Data was analysed through thematic analysis (Braun and Clarke, 2006). The posts were analysed to search for the most relevant themes to the research questions. Once the thematic patterns were established, the researcher selected the most relevant quotes that resonated with the central idea of each theme.

To make the qualitative analysis more rigorous preliminary codification was shared with the orientation team to validate and make the necessary alterations. In the initial phase, the researcher conducted a systematic reading of the posts to identify underlying meanings and emergent patterns within the data. The focus was finding more

prevalent themes that were relevant to the questions in study. The data were first transcribed to ensure that all relevant information was accurately retained for analysis. In the second phase, the researcher generated initial codes by systematically identifying salient features within the data. These codes often reflected recurring phrases, words, or conversational patterns that appeared frequently across the dataset. This helps to underline possible themes. In the third phase themes are defined. The codes are analysed and organized in broader themes. In this phase were found fourteen themes, each one with excerpts from the data to illustrate. In the fourth phase, the themes were reviewed to refine them and create more consistent themes that placed more emphasis in the research questions. These reduced the themes to three, those themes being open enough to go more in dept with some subthemes. To help in organizing the themes a revision was requested and made by another investigator. In the fifth phase the themes are defined and named. In this process the "essence" of each theme is identified and it´s determined what each theme captures. For each theme is identified why it is important and how it replies to the questions of the study. The sixth and last phase is the final analysis and the report writing. The extracts from the data illustrate the different themes found and the narrative helps understanding what was found and how the data relates to each other and the study questions.

To determine the most relevant posts on Reddit related to coping and genetic testing, the researcher initiated the search using specific keywords to locate pertinent posts and communities where there were comprehensive accounts of such situations. The keywords used were testing, genetic, coping, genetictestingdisease, geneticdisease, testingresults, afraid of genetic test results disease, afraid of genetic test results,genetictestresultsafraid. These keywords were inserted on the reddit search engine to look for posts with these themes or similar. Out of the communities that were present the ones chosen were r/cancer, r/Huntingtons, r/ataxia, r/ALS (esclerose lateral amiotrófica), r/AskDocs, r/rarediseases, r/BFS (bening fasciculation syndrome), r/breastcancer, r/BRCA. These communities are very active and there is a good amount of posts were people share their experiences with genetic testing and their coping strategies.

This search yielded 26 posts across these communities and the comments and interactions that followed. These posts were gathered between 29 april and 8 may of 2025.

Each online community has a different dimension of participants since some of them are used by people with rare diseases, making the community smaller, and others have a more generalized focus and by extension being bigger. r/cancer has 75.000 members, r/Huntingtons has 3.300, r/ataxia has 648, r/ALS has 7.900, r/AskDocs has 699.000, r/rarediseases has 5.500, r/BFS has 8.300, r/breastcancer has 35.000 and r/BRCA has 4.900 members.

The participants selected for this analysis comprised individuals who had already been affected by a hereditary condition, as well as those who were confronted with the decision to undergo genetic testing due to the presence of a hereditary illness within their family. Individuals currently in the testing phase were also included, as they experience distinct challenges, such as the anxiety associated with witnessing the effects of the illness in their relatives and the fear of manifesting similar symptoms themselves.

In this study 176 individuals were studied, both posts and comments were counted as participants. Out of these individuals 38 identified themselves as woman and 4 as male, this difference can be attributed to the fact that when a woman posts the information of her gender the comments usually follow in giving the same information, often the users that reply are woman as well.

Results

The results of this study involve an analysis of the people´s narratives accompanied by illustrative quotes for each individual theme. In this analysis three major themes were identified: Reddit as a place to speak, reddit was a support space and reddit as an emotional support space. These themes reveal the interconnection between them contributing to a comprehensive understanding on how the people that get a positive result for a disease in a predictive genetic test cope with the results, offering a valuable insight for future research and intervention efforts.

“Space to speak”

Individuals that are passing through their testing journey are often plagued with uncertainties about what the future holds for them during the testing phase and after. These individuals then seek others that have gone through the same experience in the past in an effort to know more about **what to expect in the future**. A subject that is undergoing predictive genetic testing often show signs of uncertainty about the future and afraid of possible regrets in knowing their possible chances of developing a certain disease.

Posters (the people that do the post) shared their doubts about the future and how their lives might change due to the diagnosis and in reply the community shared the struggles they had to face and the strategies used to deal with them. In case the poster is more specific with their concerns, users (other members of the community) will try to answer those concerns with their own experience in using certain strategies.

“What are your experiences with genetic testing? How did it change your life? Do you have any regrets? I have neurodegenerative symptoms (tremor, ataxia, neuropathy, cognitive decline), and I have a pretty good idea of which disease to test for. I'm terrified though. If it's what I think it is, it's not treatable, probably won't be in my life time, has a poor prognosis (although progression is often slow). I'm worried about how a diagnosis will affect my social/dating life. I'm worried that finding out will cause me stress and that stress will accelerate progression (I have clearly noticed accelerated progression during times of stress!) If I'm wrong though, there could be a treatable cause that we're missing, although the common ones like MS and vitamin deficiencies have already been ruled out. I have had a full neurologic workup, clinical exams and MRIs, but have not yet had any genetic testing. Is ignorance bliss, or did you find your life got better after knowing? I know this is highly personal, but it's hard for me to wrap my head around it.” (getting genetic tested for hereditary ataxia, 38 years old, showing symptoms for 6 years).

Some individuals seek to know other´s experiences after receiving the results to understand better **what can change in their life’s and how to deal** with the challenges that an unfavourable diagnosis in the genetic test for a hereditary disease may bring. Individuals try to seek their own answers by searching online and getting informed by people that are facing the same situation.

"To those of you who have been tested, how was your mental health and overall happiness before and after? Are you glad you did it? Do you regret it?" (diagnosed with HD)

This request for sharing experiences and stories entail an exchange of experiences between the poster and the people that reply to them. There was also a **sharing of tips** that arguably make the testing process easier, and encouragement to undergo testing as a way to be prepared. The commenters also expressed possible outcomes if the results come back positive and possible next steps that have to be taken.

*"You reminded me of me when I was going down the huntington's path. You really need to write down your main symptoms then genetic panel test. To truly nail down what you have before genetic confirmation is insanely difficult. I managed to do it but only because I trained for 12 years in investigations/law enforcement and I have a heavy medical background! So whatever is worrying you, stop worrying about it being a specific disease. Get concerned about symptomatic treatment (find ways and aids to help with your current issues) and go get the genetic testing done. Wait for the results from that then go back through the results and you should be able to start pinning symptoms to certain genes. I'm doing it now with the three I've found."(*diagnosed with HD)

People sought reddit in different phases of the diagnosis. Some prefer to look for experiences with the genetic testing before doing it so they can be prepared for the process. Other individuals seek the group support after they have their predictive test results so they can be prepared for the challenges the disease will bring. Some of the people that have their unfavourable result are already manifesting the disease symptoms, in that case they look for ways to be more informed about the disease and options they can take in the management of it or cure if possible.

"Support space"

Commenters shared the resources that they used to seek for information. They shared the **symptoms of the disease and the expected progression** based on their own experiences. The following excerpt exemplifies a comment to a post sharing the similar concerns the user had.

*"this is so super helpful! this sounds remarkably similar to my friend's condition. his muscles are overactive, and he gets muscle spasms. he experiences muscle pain with things so little as walking for an afternoon, and he can't do any rigorous exercise (his PT actually determined it was causing more harm than good). in addition he has a cleft lip and pallet and a cleft nasal deformity, a fatty liver, and occasionally blood in the stool (this isn't all necessarily related, his entire family has a mix of genetic disorders so it's honestly not unlikely that he has several unrelated conditions). i'll definitely send him the article and all this information. thank you so much!!!!"(*individual trying to help a friend identifying their rare disease,comment)

It is also shared **clinical options to manage the illness**. These options can go from small physical exercises to help with the pain, medication recommendations, possible preventative surgeries and professionals that can help.

"As far as tremors go, try to stay away from caffeine and maybe invest in a small electric massage device. I have one that sticks on my back, I think it's called a TENS unit, but it's the only thing that seems to work for my tremors. But as far as balance goes, do some core exercises and a lot of stretching. Definitely keep active."(individual diagnosed with a form of ataxia)

By looking for information about their condition, patients can advocate for themselves and be more confident. Information gives them empowerment to pursue the options available and the confidence to speak to their doctors about concerns they may have and alternative treatment options. There was an emphasis in knowledge as power to understand better their own bodies, the illness they were diagnosed with and all the available options for preventive treatment and illness treatment. Knowledge also helps to understand the ways the disease can affect their family and the possible prevention methods available for the ones that still are asymptomatic (example: preventive surgeries). If the disease is untreatable or lack preventive measures, the focus is on the knowledge to try to help manage the symptoms and mitigate the impact in their daily lives.

"*I'm glad I took the test because my original plan was a lumpectomy, but with BRCA2 I am at high risk for a second breast cancer, so I got a double mastectomy. Also this means there are endocrine treatments that work well for BRCA 1 or 2 carriers that*

can reduce my risk of ovarian cancer and recurrence." (woman, 36 years old, stage 2 breast cancer, diagnosed one year ago)

"Emotional support space"

In an effort to cope with the emotions and feelings attached to the experience of doing the genetic test and finding out the unfavourable results, individuals may try to find people and groups that share the same struggles or have gone through the same emotional experiences.

"Any ideas/tips on how to properly deal with the emotions and bad news? Any and all ideas/tips are very much welcomed, as I have no idea what I'm doing, what I should do or what I could do." (diagnosed with colon cancer in the present year, has an APC mutation (lack of tumor suppression gene))

"I'm at an age where I want to start looking at starting a family with my partner but I feel like I can't make any decisions like that until I know as I absolutely do not want to potentially pass this gene down. My concern is that I need to know, but in any event, if I am gene positive, I can't tell my mother as she does not want to know, and I wouldn't want to tell my brother either until he's ready to be tested. If I'm gene negative, although that would be great, I realise that my mother may still have it, as well as my brother. I'm kind of at a cross roads and feel like I'm ready to know, but also feel like it's a huge weight to carry a secret. I feel like emotionally I'm ready, and I've started the referral through my GP to the genetic counsellors so I will await the process to go through, but I can't stop worrying that my life will be completely different if I find out? I know that I can't change anything regardless and the benefits of knowing outweigh the cons, but I feel really alone thinking about it sometimes.

Can I still even take out life insurance? Is it the right choice that I keep the results from my family members, has anyone else experienced this? I have so many questions!" (woman, 27 years old, living in UK, getting tested for HD, not showing any symptoms)

Online forums offer the chance for the subject to share difficult emotions such as anxiety and uncertainty in taking the decision to do a predictive genetic testing. In return other users share their own experiences with predictive genetic testing, how the decision affected them and all the emotions they had to manage during the testing and when they got the results. This allows for a sharing and validation of emotions. Users also shared strategies on how to deal with the emotions.

"I found out at a young age, I had a lot of anxiety and paranoia for a while, but it's gotten so much better. Preventative care can be stressful but it's helped me knowing im doing what I can to lower my risk. Over time I learned not to obsess over it and learned to live in the present. There are moments of anxiety here and there but it's much less.The knowledge may feel like a curse, but many people don't get the chance to have this knowledge before getting cancer. Knowledge is power, and it can be used to our advantage!

Take your time to process, I promise it does get much better with time!" (posted on BRCA subreddit).

Some of the strategies that were shared are seeking the support of family members, talking with a mental health professional to help process the emotions and seeking a genetic counsellor that could help with the feelings and also explain any doubts and concerns about the illness or the genetic testing process. Strategy sharing helps giving the poster some sense of control and possible directions on what to do next and the emotional experiences that can come with it, preparing the subject for the possible future outcomes.

"(...)3.I signed up for therapy and I start next week. It will be nice to have someone impartial to vent to. I'm hoping that I can work through my fears and anxieties in a more productive way than crying on my bathroom floor.

4. I have kept my diagnosis private. I'm not ready to people to know, and I'm not sure when I will ready. But hopefully therapy will help me overcome this hurdle.

5. I've cried. A lot. Sometimes, I'm ashamed of how much time I've spent feeling sorry for myself. But BRCA is an absolute gut punch. We shouldn't be ashamed of being sad or emotional. I'm trying to allow myself the grace to feel my emotions as they come. (...)

7. I'm trying to earnestly look on the bright side. I don't have cancer. I am strong. I can handle this. Hell, maybe I could come out of this with a lovely new set of boobs. At least that would be a good consolation prize?

All that being said, I'm new to this. I'll probably have a good cry this evening once I log off work. But that's okay. It's all part of the process.

Happy to talk more if you (or anyone else!) needs someone chat with. This diagnosis can be very isolating, but I don't think it has to be. I'm thankful for this community and its members.(...)"

Users that share their emotions and concerns with the group reported that they felt their worries were more validated and eased their anxiety. Posters felt a sense of community and that they weren't alone in facing the same struggles.

"Seeing other people living and thriving after BRCA diagnosis was inspiring."

"And remember there have been millions of women who ran this race so we can walk it. It's not a club I wish anyone in, but it's a damn good club for support and having information. I hope you feel a bit better about it." (woman, BRACA2 gene mutation, diagnosed last year with the mutation, no cancer)

The experiences shared aren't always negative, there are some replies to the posts that outline the positive experiences and feelings after they had come to terms with their diagnosis. Users outlined the importance of experience the emotions that come to them and as well as reaching for support channels that are available. Emotions should be understood so the person can understand better themselves and focus on the possible solutions to help with the coping process and the feelings that come with it. Coping is viewed as a process that takes time and its different from person to person.

"Community Space"

In the active engagement measure we could observe an effort by the community to involve the new member in the group. New members are welcomed to the subreddit by other users and incentivized to post and talk any concerns. There is an emphasis on the role of the group in offering means of support and venting. Members shared constructive opinions and ideas to help with problem solving and share their feelings.

"Hey! Sorry you've joined this shitty club, but there's an amazing community here to help!" (stage 3 breast cancer, diagnosed 4 years ago)

(...)" This is a really good community for support and Info. It helps so much to be able to talk to ppl who know what you're going thru. Somehow it makes it more okay when you can at least say "hey, I'm not crazy/overreacting, look how many other ppl had these symptoms too." (Just my opinion anyway)(...)" (individual diagnosed with HD, symptomatic)

Discussion

Predictive genetic testing can trigger difficult emotions, be it before the actual testing process and after with the waiting for the results and the arrival of them. Rolland & Williams (2005) Family System Genetic Illness model identifies psychosocial types and phases of chronic disorders. For disorders in which the carrier, predictive or presymptomatic testing is available, there will a longer period of adaptation and challenges on the pre-testing and post-testing period compared to the symptomatic carrier. The challenges faced by the individual may change due to key disease variables such as the likehood of developing the disease based on the specific genetic mutations, overall clinical severity, timing of the clinical onset in the life cycle and whether effective treatment interventions exist to alter disease onset and/or progression. This study aimed at exploring/examining the coping mechanisms employed by individuals that received their unfavourable predictive genetic test result or the individuals facing the testing process.

During the analysis of these reddit communities it was evident that the communal connection was present even if the group was not "physical". Users interacted with each other in a similar manner to the patient groups that interacted in the real world with the exceptions that reddit communities have members all over the world and they are all anonymous. The different subreddits don't just function as a place to post some questions and get answers, it serves as a place of community where an individual can find people with similar concerns, experiences and most of all same genetic disease.

There isn't just a simple sharing of posts, users create and seek the advantages of a community where they can openly share with other people that are in similar situations about their struggles and share ways to cope with the different challenges that come with getting a positive result for a genetic disease through a predictive genetic. This is a coping mechanism itself, a process called communal cooping.

Communal coping is a process in which a stressful event is substantively appraised and acted upon in the context of close relationships (Lyons et all., 1998). *A shared illness appraisal is one individual´s perception that the responsibility to manage the illness is a joint or shared- that is, it is "our problem" rather than "my problem" or his/her problem".*

Members may also come to understand one another´s illness appraisals through day-to-day communication about the illness. Individuals who have a shared illness appraisal are likely to communicate more about the illness (Lyons et all., 1998), leading members to share knowledge, learn about the illness together, and have shared expectations for illness management.

Collaboration reflects joint input, mutual effort, and a team approach to successfully manage a problem (Berg, Wiebe et al., 2008; Berg, Schindler, Smith, Skinner, & Beveridge, 2011). When the illness is chronic the issue is illness management.

Helgeson et al (2017), defined measures that tap collaboration:

Active engagement

Involving a member into the discussions, inquiring how they feel, and other constructive problem solving.

Common dyadic coping

Members participate in the coping process more or less symmetrically or complementary in order to handle a problem-focused or emotion-focused issue relevant to the dyad by using strategies such a joint problem solving, joint information seeking, sharing of feelings, mutual commitment, or relaxing together.

Collaborative strategies

Strategies in which partners are perceived to be actively involved as collaborators, by taking equal responsibility for action, brainstorming, and negotiating. The measures that tap shared illness appraisal are: **We-language,** percentage of words or percentage of pronouns that are first person plural (we,us,our) in the context of an illness discussion with a member. **Appraisal of responsibility,** partners brought together to reach an agreement as to how they viewed the illness management as a couple: a patient's problem to manage, a patient's problem to manage but that affects both of them, their problem to manage as a team (coded as shared responsibility).

Following the measures that tap collaboration by Helgeson et al (2017) we can find some of the measures to identify communal coping in virtual groups.

In the active engagement, users frequently share their own experiences and emotions and in turn ask the other users about their own feelings and perspectives in relation to the theme that has been discussed in the post.

In the common dyadic coping members show a complementary coping strategy by sharing strategies they used to deal with similar problems and giving some advice to the members on how to do the same or other possible solutions based on the specific problems the users share. Members also share information that is relevant to the problem and offer guidance to find more resources so the user can do their own research as well. Users also share doubts and experiences to try to find people that are going through the same so they can find solutions together and share what it worked or not for them. Members also share a joint commitment of "fighting off" the illness, in the case of a curable one can be the commitment to do their best in their "path" to a cure, or in the case of a incurable illness doing their best to manage the symptoms and still manage to follow with their life plans to the best of their capabilities.

In the collaborative strategies it was more difficult to find evidence for this since this is an online group constituted by anonymous people from different parts of the world. The most visible aspect of this measure was by the effort that users make in helping each other. Is frequent to see posts of individuals with concerns and doubts about specific topics and those being answered by users that make their best to advice based on their experiences.

The subreddits users showed a “we” language very frequently. That language shows up when discussing the similar illness and with support messages. Members view the illness as a collective issue and one where they try to fight together. When also welcoming the new user, members talked about the group importance and the help that everyone can give. Users also reported that the subreddit makes them not to feel so lonely and that it gives a sense of having a big group of people that are offering their support all the time.

On the appraisal of responsibility, the community clearly viewed the illness as an issue that affects all of them and they are all actively managing together. This can be easier achieved since usually the users have the same illness, so they feel like their struggles are shared. In the case that the illness isn’t shared, for example in the subreddits dedicated to more rare diseases, there is still a sense of team management for the problems that any phase of the illness or genetic testing can bring.

These different measures have shown that communal coping can exist in the context of online communities not being restrictive to family or close people in the life of the individual.

The majority of the research about communal coping is focused on the interactions with the patient’s family or partners. This translates in that the measures given for communal coping being more focused on the attitudes, thoughts and actions of the people that are the closest to the patient.

Internet communities are a space that can provide the same benefits of communal coping without it being just restrictive to family or partners. Subreddits offer a space where individuals can identify with others since most users there have the same illness, condition or made the predictive genetic test. Individuals come to these groups as also a way of coping by trying to find other people with same experiences or that had the experience some time ago in search of tools that will help them manage the illness and their emotional state (Ashtari, & Taylor, 2022).

The sharing of possible solutions and discussing ways to deal with the issues exposed is a sign that collaborative thinking on the strategies used is employed. Still, the online members cannot take responsibility for the actions that the poster may take after the discussion has been made.

These different measures have shown that communal coping can exist in the context of online communities not being restrictive to family or close people in the life of the individual.

A person facing the dilemmas that come with predictive genetic testing and the stress it causes will try to find ways to cope. One of these ways is searching online for communities as a way of coping and as well as finding different strategies to deal with the challenges that the individual is facing or might face. The community is also helpful in giving tips to communicate more effectively with family and partners reinforcing the support systems that the person may already have.

Knowing what to expect and possible ways to act gives tools to the patients that allow them to decide for themselves on what they think is the best course of action. More informed patients also can plan ahead and modify their life projects in accordance to changes they are facing or will face.

There is still the need for research that focus in the communal coping that online communities can bring, studies that would focus on the interactions and support that members of online communities can bring and the coping strategies a group of people that share the same concerns and experiences. There is also the need to make models of communal coping that are more focused on groups than on family or partners.

Limitations

One of the limitations that data from online forums relates to potential representativeness and verification challenges that arises from the contributor's anonymity. The anonymity makes it harder to extract any socio-demographic data from the studied sample.

There is also the fact that the chosen online communities that are in this study don't represent every online group that can be found on the internet. Reddit is a platform with its advantages and limitations of which can be different compared to a forum or even a Facebook group. Different online platforms have different ways that users can interact and those differences must be taken into account. For example, some online forums don't

permit private messaging so the users can't privately interact with each other like on Reddit or Facebook.

Since on Reddit we can only observe posts and the interactions that come from those in the comments it's hard to have a follow up on the copping methods used and advice given to the poster. This makes it hard to know the effectiveness of this strategies on the long term.

The use of specific keywords for the search that relate to suffering and anxiety may have skewed the data to report of individuals with more negative experiences related with genetic testing and hereditary disease.

Is also important to note that posts made by the users in this study may lack comprehensive descriptions about their diagnosis and coping "journey". This could come from potential reluctance or selectiveness in revealing too much personal details, or the user just sharing enough to be able to get prompt responses from Reddit.

Conclusion

In sum this article explores coping mechanisms that can be found in online community spaces by analysing Reddit posts. From the posts it was possible to observe the interactions of the users and perceive the use of communal coping as a strategy to overcome the challenges that a diagnosis with a rare genetic disease can bring.

By using the model of communal coping of Helgeson et al (2017) there could be identified in what ways communal coping is manifested in online communities. These manifestations were studied by analysing the contents of the posts and the interactions that came from them. The community interactions show a group effort in dealing the emotions, feelings and challenges of rare genetic illness in the different phases, predictive genetic testing, asymptomatic, symptomatic.

These interactions show that communal coping can be seen even in groups where the users are anonymous and don't share previous emotional connections.

For future studies it would be advised a more refined model of communal coping where it takes into account the possibility of communal coping in online communities, examine the differences between the manifestation of communal coping in an online and offline setting and descriptions on how the communal coping changes over the course of a chronic illness.

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