**Social Media Use: Rare Disease Patients, Caregivers, and Parents**

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**Executive Summary**

The report that follows aims to assess the disconnect between the rare disease community and healthcare businesses. Pharmaceutical companies, political entities, hospitals, and professionals are providing insufficient funding, support, attention, and guidance to those living with rare diseases. This has left these individuals with a lowered quality of life, unequal care, and lacking knowledge of options and solutions to their ailments. The literature review illustrates the problems many different individuals face, from patients to caregivers to healthcare professionals. It encompasses the following topics: current literature and studies, a background on rare diseases, patient mental health and support, the theory of belonging, social media support groups and medical information, families, and caregivers, and lastly, impacts and problems related to healthcare professionals. From this analysis of the current landscape, five hypotheses were formed. These pertained to topics like information on social media, uses of medical information, support, mental health impacts, and awareness of treatments. These were tested via a survey, which was outlined in detail in terms of materials and methods that were used to conduct the primary research. Limitations like the unequal geographic distribution of respondents were discussed within this section as well. The data was analyzed using a mix of correlation, ANOVA, and t-tests to obtain results. The findings showed multiple strategies that could assist in closing the gap or disconnect between the rare disease community and healthcare businesses. These strategies include using social media to promote therapies, collaboration amongst health2care professionals and businesses, and the overall use of the platform Facebook for healthcare companies. The study concludes with suggestions going forward for those who want to dive deeper into this problem, such as diversifying the rare diseases and geographic locations surveyed.

**Social Media Use: Rare Disease Patients, Caregivers, and Parents**

With social media becoming an integral part of our everyday lives, it is paving new landscapes and changing industries in unprecedented ways. The healthcare industry has evolved rapidly as the public turns towards social media for social and informational support (Moorhead et al., 2013; Dalmer, 2017).For those with common medical conditions, seeking out like individuals and gaining support from their providers is easier. It is uncommon for patients with rare situations to find others with the same ailment within proximity (Titgemeyer & Schaaf, 2020). Rare diseases are categorized as affecting less than 200,000 people in the U.S. (National Human Genome Research Institute, n.d.).There are more than 6,800 different rare conditions, with the rare disease category of inborn errors in protein metabolism being the focus of this research problem. In general, rare diseases are often undiagnosed, and there is limited information and resources, geographically sparse support groups, and an overwhelming feeling of social isolation (Pelentsov et al., 2016). Due to this and the lack of knowledgeable providers, resources, attention, and support associated with rare diseases, social media support groups are particularly vital to this group (Pelentsov et al., 2016). Friends, family, caregivers, and patients find these platforms helpful in sharing and providing experiences, advice, information, treatment, diagnosis, coping strategies, and emotional support (Ashtari & Taylor, 2022).

Moreover, in pediatric rare diseases, parents who have experienced extreme social isolation before joining these groups now have increased connections, family harmony, and lower stress levels (Titgemeyer & Schaaf, 2020). Providers and businesses can learn more about the unmet needs of the community and share therapies and research with a larger audience(Zhao & Zang, 2017). Despite the long list of positives, providers, professionals, and patients with rare diseases are concerned that the information passed through social media support groups is unreliable (Ashtari & Taylor, 2022).This can create problems when making personal health decisions based on the posts seen on these platforms without discussing them first with their healthcare provider (Dalmer, 2017).This mixed view of whether social media is helpful to the rare disease community is largely under-studied but beneficial as the healthcare industry evolves and grows.

Due to this unexplored area, the problem is: How does social media impact the rare disease community regarding social and informational support, research, and advocacy?

This research aims to examine the effects of social media on the rare disease community from a multi-faceted perspective. Due to the enormous scope of this question, it has been broken down into three research questions. These are as follows:

1. What are the attitudes towards the medical information available on Facebook and Instagram support groups for rare diseases?
2. Will the patients, families, and caregivers feel more supported through social media support groups?
3. Do patients, families, caregivers, and professionals have better access to treatments on social media?

**Literature Review**

**Current Literature and Existing Studies**

Although there is a gap in research on the target group of rare disease patients, there are other existing studies regarding social media use and its effects on other patients with medical diagnoses. In interviews with cancer patients, data suggested that individuals mostly used private groups on Facebook but mentioned the use of Instagram as well to manage their care (Lazard et al., 2021). On these platforms, they, on average, discussed information regarding their symptoms, diagnosis, and lifestyle. Social support was a primary reason for seeking out social media regarding a cancer diagnosis (Lazard et al., 2021). This connection is seen to exist during the diagnosis, duration, and post-cancer stages of their condition (Lazard et al., 2021).

**A Background on Rare Diseases**

In 1970, families, caregivers, and patients with rare diseases felt isolated, forgotten, and were left helpless due to the lack of research, funding, and treatments (National Organization for Rare Diseases, n.d.). By the 1980s, coalitions formed to advocate for improved care and access to medical treatments, combining to make the National Organization for Rare Diseases in 1983. During that same year, the Orphan Drug Act was passed, and it incentivized companies in the industry to create treatments for the rare disease community (Swann, 2018). Today, despite the approval of over 500 new therapies, 90% of those living with at least one of the 7,000 defined rare diseases have yet to have any treatments (National Organization for Rare Diseases, n.d.). Even for those fortunate enough to have a treatment available, only one in every ten individuals takes them. This can be due to the high price, availability of resources, or knowledge of treatments (Ministry of Health and Family Welfare, 2021)

Effecting a population of more than 300 million globally, rare diseases are less rare than commonly thought (Miller et al., 2021). Within the United States, rare diseases affect one in less than 200,000 people and tend to be genetically transferred from parent to fetus. While rare diseases vary in symptoms, diagnoses, and treatment, they can be categorized as conditions that often go undiagnosed with limited information and resources available to them (Plentsov et al., 2016; Titgemeyer & Schaaf, 2020). Additionally, there are geographically sparse support groups, and their disease affects multiple bodily systems, including the mental well-being of the patient (Plentsov et al., 2016). Rare diseases also have an impact that spans far beyond the patients. With considerable catastrophic repercussions on family units and their healthcare professionals, the implications of rare diseases span physical boundaries (Currie & Szabo, 2020).

With a lack of help, assistance, knowledge, and care from providers and healthcare professionals, patients and families with rare diseases are left to manage their care on their own (Miller et al., 2021). Moreover, if they have side effects or repercussions from their original diagnoses, they will require more specialists to assist with their multi-system care (Miller et al., 2021; Plentsov et al., 2016). Governmental support and funding from the Federal Drug Administration regarding treatment approval and aid are insufficient (Miller et al., 2021). Pharmaceutical companies interested in developing therapies for a specific rare disease often find the recruitment process complex, time-consuming, and expensive (Miller et al., 2021). They also find it challenging to produce a treatment or therapy due to the lack of understanding of these conditions and their often involvement with multiple bodily systems (Food and Drug Administration, n.d.).

**Patient Mental Health and Support**

As a patient navigates their health journey, it is vital that they receive significant support in a multi-faceted way. This support can come from family, peers, and medical professionals; however, it is also critical that the patient receives support from a community of individuals who can relate to their situation. Low emotional support levels have been associated with poor medical outcomes, progression of symptoms, and a higher risk for mortality (Flavin, 2015; Shensa et al., 2017; Ventola, 2014; Wright, 2016; Zhao & Zhang, 2017).

Due to the rare disease community's sizeable geographic separation, their support primarily happens via social media. Additionally, people with rare medical conditions report low levels of support from their healthcare providers, peers, and, in some cases, immediate family members. This makes social media a vital tool to ease feelings of isolation and increase the sense of belonging (Currie & Szabo, 2020). The theory of belonging states that as users gain autonomy and self-expression online, a strong connection between the user and the platform will occur (Wang et al., 2021).As this happens, one is compelled to seek recognition and acceptance on social media (Wang et al., 2021). Rare disease patients have been known to face similar problems to those with more common conditions. However, due to the scarcity of the ailments, they have more situations to deal with than common medical diagnoses. With severe devastation occurring in these communities, they are often battling with poor mental health levels due to the intense stigmas and exclusion they experience (Flavin, 2015). Additionally, in contrast to patients with chronic illnesses, an individual with a rare condition often goes undiagnosed due to the limited information and resources available (Pelentsov et al., 2016). This furthers the isolation as late diagnoses can impact many functions regarding the ability to process and communicate with peers.

As mental health enters the conversation, health care has evolved to address the patient as a whole. Caring for a patient's psychological health in conjunction with their medical health is vital to ensure that the individual thrives and their quality of life increases (Flavin, 2015). Those with chronic medical conditions find themselves more vulnerable to additional mental health diagnoses (National Institute of Mental Health, n.d.). Whether it be a direct symptom of the specific condition or a product of being socially isolated and lacking a sense of belonging, patients with chronic medical conditions often have symptoms of depression and anxiety. This affects a patient's ability to adapt to their treatments and may impact medical costs due to added needs (National Institute of Mental Health, n.d.). Additionally, poor mental health can be related to an increase in additional medical ailments and higher morbidity rates (National Institute of Mental Health, n.d.).

Due to these consequences, it is vital that rare disease patients receive the support they lack. There is insufficient assistance from family members, peers, and providers; therefore, they are struggling to improve their mental health (Cardinali et al., 2019). These individuals would be categorized as “prosumers” as they have the most minor support outside the online platforms (Fergie et al., 2016). They often seek the information, assistance, and connection they desire through social media and other online sources (Fergie et al., 2016; Yabumoto et al., 2022).

**Social Media Support Groups and Medical Information**

Social media platforms such as Facebook, Instagram, Twitter, YouTube, and more have integrated themselves into our daily lives (Fergie et al., 2016; Van Dijck, 2013). These online sites and applications have grown into an in-depth network where users seek information on everything from health care to daily tasks. The platforms themselves are shown to have different uses. From a medical perspective, Facebook has been shown to achieve patient needs more effectively due to its algorithm, structure, and policies (Gurler & Buyukceran, 2022). Additionally, with the introduction of social media support groups, users have found a way to belong in terms of their medical care regardless of time zone or geographic boundaries (Miller et al., 2021).

Social media support groups have been seen to exist for common ailments but also rare diseases and are growing in popularity exponentially (Miller et al., 2021; Wright, 2016). Rare diseases are classified as being chronic, critical, and continuous while also occurring in one out of every 200,000 people in The United States of America (Food and Drug Administration, n.d.; Titgemeyer & Schaaf, 2020). Rare diseases often are underfunded, lack resources, and leave individuals vulnerable to psychological, social, economic, and cultural factors (Titgemeyer & Schaaf, 2020). Due to the prevalence varying depending on the geographic area, there is also inconsistent support and resources globally (McMullen et al., 2020).

Individuals with common ailments find it easier to meet people with similar circumstances and often are provided with research, knowledge, and support in their everyday lives. Patients with rare diseases are often geographically separated and find it difficult to seek a person within proximity with the same diagnosis (Titgemeyer & Schaaf, 2020). This puts strain on both the individual with the condition and the family unit. Due to this geographical separation, rare disease patients often come together on social media support groups to discuss the daily struggles of life with an uncommon condition and to express the unmet needs of their medical care (Pelentsov et al., 2016). Additionally, they utilize these platforms for informational and social support, advocacy, and research (Miller et al., 2021).

Those using social media support groups have found that they can read and participate on their own time, which makes access easier as there are often differing time zones due to geographic separation (Wright, 2016). Additionally, some social media sites have an option to remain anonymous, creating a judgment-free zone for medical support (Wright, 2016). It is even suggested that these online platforms give patients a way to personalize their health care and gain self-efficacy over their medical decisions (Dalmer, 2017; Oh et al., 2013; Wright, 2016). Individuals also turn to social media for information because it eliminates medical jargon that can be difficult to understand and impacts one’s ability to understand their care (Lazard et al., 2021). Some even find that social media helps fill the gap between daily life and the more traditional information their doctor provides (Smailhodzic et al., 2016).

Social media support groups are also a place of advocacy and primary contact between patients and businesses that can provide new therapies or politicians who lobby for new policies. Better access to a more concentrated number of patients makes recruitment for clinical trials and new policies more accessible than ever (Miller et al., 2021). The data taken from social media regarding rare diseases could give vital information on life with a disease, the outcome of patients, and the quality of life for those affected (Miller et al., 2021).

A variety of discussion topics take place on social media support groups. One prevalent one is life with their specific medical condition and daily struggles (Lazard et al., 2021). Social media support groups for medical diagnoses, in general, can be seen to contain this topic of conversation, with threads about symptom management and coping strategies (Ashtari & Taylor, 2022; Lazard et al., 2021; Pelentsov et al., 2016).

Another significant discussion topic is the passing of medical information on social media support groups. From conversations about medications that relieve adverse symptoms to outstanding clinical trials, treatments, and drugs, healthcare information is passed instantaneously daily (Lazard et al., 2021). Additionally, they discuss parts of treatment or medical care that are uncertain or confusing in hopes of receiving advice or information on how to proceed with their care (Lazard et al., 2021).

Despite the positive effects of information on social media, it can also have adverse impacts when the medical information is wrong or unreliable. Due to these platforms being a fast-paced environment, it is tricky for professionals or moderators to find, flag, and correct misinformation before it has been seen by users (Dalmer, 2017). Additionally, with individuals posting their own medical experiences, verifying the information within posts is difficult (Dalmer, 2017).

Users fall into one of two categories regarding health information on social media. They either believe what they read regardless of the reliability, or they distrust the information on the site. If a person who trusts medical information on social media comes across poor advice and does not consult their provider, it may lead to a dangerous decision in terms of their care (Dalmer, 2017; Lim, 2016; Moorhead et al., 2013; Ventola, 2014). Generally, there is distrust regarding the advice and information seen on social media (Ashtari & Taylor, 2022; Zhao & Zhang, 2017). However, with the lack of support and resources available for rare disease patients, they are left more vulnerable than most to unreliable information (McMullan et al., 2020).

**Families and Caregivers**

Living with a rare chronic medical disease often has effects that extend beyond the patient (Cardinali et al., 2019; Currie & Szabo, 2020; Xu et al., 2021).Multiple people care for and are impacted by these conditions from childhood to adulthood. Parents, siblings, spouses, friends, and peers, in some way or another, must adjust their lifestyles and habits (Cardinali et al., 2019; Currie & Szabo, 2020; Xu et al., 2021).

Caregivers of pediatric patients often experience immense negative mental health repercussions (Currie & Szabo, 2020; Pelentsov et al., 2016).They often feel socially isolated and disconnected from other parents and society in general (Titgemeyer & Schaaf, 2020). For the rare disease community, caregivers often do not come across other families with similar circumstances. In the rare occurrence they have, they experience a unique connection that is difficult to find in everyday life (Currie & Szabo, 2020).

Additionally, those caring for a person with a rare condition often face more challenges than those caring for a more common ailment (Cardinali et al., 2019; Xu et al., 2021). For example, it is common for people with rare diseases to experience unique issues in their health care, lack of information about their disease, delays in diagnoses, below-average treatment options, and inadequate access to health care (Xu et al., 2021).

Moreover, regardless of the age of the individual with a rare disease, caregivers and parents face many mental health struggles. Parents can feel isolated from society, experiencing mental health diagnoses and financial burdens concerning their child's condition (Pelentsov et al., 2016). There is also a lack of sharing when it comes to experiences due to a fear of misunderstanding and shame. Mothers struggle to speak up as they often fear the assumption of being a poor caretaker if they express their hardships (Currie & Szabo, 2020). They often feel frustrated and helpless when it comes to their child’s care and the lack of understanding from their surrounding peers. Caregivers report feeling exhausted and isolated regarding support from their geographic community (Currie & Szabo, 2020). These parental figures develop harmful conditions and dangerous habits from the adverse effects of having little to no social support (Cardinali et al., 2019). This decrease in mental and physical health impacts their ability to care for their child’s condition and, therefore, affects their medical outcomes (Xu et al., 2021).

Parents also have been seen to face long-term challenges and make personal sacrifices to manage their child’s condition. On top of this, they experience restricted health support and an absence of knowledgeable providers who make life-altering decisions for their children (Pelentsov et al., 2016; Xu et al., 2021). Due to this lack of support, parents are expected to have specialized knowledge to manage their child's complex condition, including making educated decisions on day-to-day care and emergencies that occasionally arise (Currie & Szabo, 2020; Pelentsov et al., 2016).

Support groups have been seen to alleviate the struggles that parents and caregivers face. They increase valuable connections, control, family harmony, and lower stress levels (Titgemeyer & Schaaf, 2020). They also increase health literacy and support and provide advice for patients and families, benefitting all members of the familial unit (Titgemeyer & Schaaf, 2020). Support groups are utilized as coping mechanisms to help combat the emotional and physical toll these conditions take on caregivers (Cardinali et al., 2019; Pelentsov et al., 2016). By doing so, these individuals can provide better support and care for a person with a rare disease better.

**Impacts of This Problem in Relation to Health Care Professionals**

Physicians and health care providers play a significant and vital role in the outcomes of their patients. The decisions and events affecting patients and caregivers impact providers and industry professionals. Additionally, regarding rare diseases, individuals and families rely on doctors to gather information to make informed decisions. The physician's point of view and state of health care for this group is vital to the background of this problem. Most importantly, it showcases the variety within this problem and explains the unique position rare disease patients are in.

Patients with these diseases tend to experience a lack of support, care, and knowledge from their specialists (Currie & Szabo, 2020; Pelentsov et al., 2016). This causes parents to take on medical roles in their child’s life and causes struggles in every phase of their condition (Cardinali et al., 2019). Patients and caregivers have described the healthcare system as disjointed and uncoordinated, impacting medical outcomes and decision-making (Currie & Szabo, 2020).

Since rare diseases require specialty providers, student doctors find it challenging to gain knowledge on these conditions as the experience is found in geographically dispersed clinics (Stoller, 2018). Additionally, the desire to work with these uncommon conditions depends entirely on their exposure and encounters with them. Due to the scarcity of these ailments, learning clinicians do not come across such situations often, furthering the knowledge deficit on these medical ailments (Stoller, 2018). This also creates a restriction in health support and an absence of knowledgeable providers who make life-altering decisions for rare disease patients (Pelentsov et al., 2016).

Beyond the patient experience, physicians have begun adopting social media technologies to connect better and build patient relationships (Lim, 2016). As a source of education for healthcare workers, online platforms can improve the outcomes of individuals with medical conditions (Ventola, 2014). This becomes vital in lesser-known conditions as it has become more accessible to learn about them through these new resources. By using the method of crowdsourcing, medical professionals can combine their knowledge virtually and solve complex patient problems (Ventola, 2014). Sharing needs and information is vital for industry professionals as it gives direct solutions and feedback to improve medical care (Lim, 2016).

Organizationally, these platforms can provide a place for others involved in health care to communicate with patients, market products, fundraise, and provide customer support (Ventola, 2014). This has been incredibly successful in promoting hospitals as it creates an accessible way to find a location that fits their needs (Ventola, 2014). Non-profits in health care have also increased their presence, increasing information flow and awareness (Ventola, 2014).

Despite the positives, healthcare professionals are hesitant due to some negative repercussions of adopting social media practices into their care (Lim, 2016; Ventola, 2014). Due to long-lasting conversations available to a large audience on these platforms, these individuals worry about defamation (Lim, 2016). Negative discussions about physicians or institutions could damage their reputation and prevent others from getting assistance (Lim, 2016).

Additionally, privacy is one concern for physicians as the media has focused solely on harmful situations, leaving little conversation regarding the valuable information, advice, and tips on these sites (Lim, 2016). Moreover, providers are concerned about the information on these platforms, which patients and healthcare professionals use as a basis for medical decisions (Lim, 2016). With unknown authors and sources, the medical information available cannot be fully trusted and relied on for these vital discussions (Ventola, 2014).

***Hypotheses and Justification***

H1: Rare disease patients, parents, and caregivers will feel negatively about the information on Instagram versus positively about Facebook. Justification: In a previous study of the rare disease, Ehlers-Danlos Syndrome (EDS), participants expressed concern about the reliability of the information online, stating that the presentation of the data was also ineffective and hindered their experience (Ashtari & Taylor, 2022). Facebook, however, has been shown to achieve patient needs more effectively due to its algorithm, structure, and policies (Gurler & Buyukceran, 2022).

H2: Rare disease patients, parents, and caregivers will use the information found on social media in conjunction with their physician’s recommendations. Justification: With an interest in online genetic counselors and a need for patient-centered care, past research has focused on the need for assistance from medical providers and support groups and how those two methods of health care impact one another (Yabumoto et al., 2022; Zhao & Zhang, 2017; Moorhead et al., 2013; Smailhodzic et al., 2016; Oh et al., 2013).

H3: Rare disease patients, parents, and caregivers will feel more support through online platforms than from their medical team or physical support systems. Justification: Studies have shown that parental and patient support groups have increased connection and family harmony and have lowered stress levels and feelings of social isolation (Titgemeyer & Schaaf, 2020; Pelentsov et al., 2016; Zhao et al., 2019). With a lack of support in their daily lives, these individuals have been seen to find support in alternative online ways (McMullan et al., 2020; Pelentsov et al., 2016).

H4: The use of social media in rare disease patients, parents, and caregivers has a perceived positive impact on their level of mental health. Justification: Past research has shown that an increase in support and a decrease in social isolation positively impact the mental health of patients and caregivers (Titgemeyer & Schaaf, 2020; Pelentsov et al., 2016). Support from a community consisting of patients with similar or the same rare medical conditions may impact the mental health of patients and caregivers as they tend to be dispersed geographically (Titgemeyer & Schaaf, 2020).

H5: Patients, parents, and caregivers will report awareness of treatments on social media.

Justification: Past research has suggested that a prominent topic of conversation on social media support groups regards treatment and symptom management (Lazard et al., 2021; Moorhead et al., 2013)

**Methodology**

**Participants**

The online survey was distributed via social media, email, Reddit, Facebook Messenger, and text message. It received 425 responses. Out of the 425,fourwere removed because they were under the age of 18. Additionally, three were removed because they were not in the target audience (patients, caregivers, and parents), andelevenwere also removed because they reported zero hours of social media use. After the data cleaning removal of 18 from the screening questions and the 100 incomplete responses, the usable sample of respondents was 303.

A blue pie chart with numbers and a number

Description automatically generatedThe final group of participants included 29males, 269females, fivenon-binary or third gender, and zeropreferred not to say. The age range of the usable sample was from 18 to over 65 years, averaging in the 35-44 range. Moreover, referencing Figure 1, participants were mainly from North America (*n*= 256) but were also found to be from Europe (*n*= 29), Australia (*n*=14), and Asia (*n*= 4). South America, Africa, and Oceania had zero responses in the survey (*n*= 0).

Figure 1:

Respondents anonymously and voluntarily took the survey and were not compensated for participation. With a consent message placed at the beginning, those who continued into the survey agreed to the uses of the data and were able to exit at any point.

**Materials and Procedure**

The survey was created online via the Qualtrics platform (see full report in the appendix). It consisted of thirteen questions and, on average, took respondents three minutes and twenty-five seconds to complete. When entering the survey, participants were given background information on why the data was being collected and to whom the survey pertains. The welcome message concluded with a confidentiality notice and an approximate duration time.

After hitting continue, participants were presented with three mandatory screening questions on separate pages. An example of the first screening question is as follows:

*Please select which statement best describes you:*

*a). I am a patient with a rare disorder.*

*b). I am a parent or caregiver of someone with a rare disorder.*

*c). I am a doctor or physician.*

*d). None of the above.*

Those who responded “I am a doctor or physician” or “None of the above” were directed to a thank you page and ended their time in the survey. Those who answered as a patient, parent, or caregiver were moved to the other two screening questions pertaining to age and social media use (see appendix below).

Those who qualified past all three screening questions were presented with a question ranking their feelings on information related to their or those they support’s condition on the platform Instagram and then the same question regarding Facebook. These questions prompted individuals to use a five-point scale ranging from one, “I feel very negatively,” to five, “I feel very positively.” This scale was kept consistent throughout most of the survey to increase the likelihood of comprehension and being mindful of the varying progression these conditions have on an individual’s cognitive processes.

Next, respondents were asked two consecutive questions ranking their frequency or likelihood of seeking information on Facebook and Instagram when they had questions about their or those they support’s condition. This was also ranked on a five-point scale from one “never” to five “every time.”

After this, respondents were directed to a matrix-style question. The question is as follows:

*Please rank how supported you feel by each of the following:*

*a). Your medical team*

*b). Your immediate and extended family or friends*

*c). Rare disorder social media support groups*

Participants were directed to rate each of these groups on a four-point scale, with one being “very unsupported” and four being “very supported.”

The following two questions had individuals think back to the last month and report how many days they used social media for their or those they support’s condition and their overall mental health level. Mental health was converted to a five-point scale, one being “poor” and five being “good.” Before two demographic questions, respondents were asked to rank their awareness of treatments or therapies available on Facebook and Instagram from one “not aware” to five “extremely aware.”

This survey was distributed on personal Facebook profiles, rare disorder Facebook groups, LinkedIn, Instagram profiles for rare disorders, email lists for rare disorder organizations, and the researcher’s personal contacts. Data collection took place over a 21-day period in the Spring of 2024. After that, the survey was closed, data was downloaded, and statistical analysis was started. T-tests, correlation, and ANOVA tests were conducted using Excel data analysis.

**Limitations**

There were a few limitations in conducting this study. The first was the location and gender of participants. The majority of respondents were from North America. Additionally, 269 identified as female, while only 29 were male, and 5 identified as third gender or nonbinary.

Another limitation was the survey distribution, which in turn created an assumed unequal representation of rare disorders. The link was posted in many support groups targeted towards specific rare disease diagnoses. While more generalized support groups and organizations were also included, there were several rare medical conditions that were more frequently contacted. Since no question was asked about diagnosis, it is unknown the actual breakdown. However, the equal distribution to more people affected by rare disorders could provide more insight.

**Results**

Hypothesis one predicted that rare disease patients, caregivers, and parents would feel negatively about the information available on Instagram and positively about Facebook. This hypothesis was supported. The results of a paired two-sample mean t-test showed that the feelings towards Instagram (*M* = 3.47, *SD* = .93) were significantly lower or more negative than the feelings towards Facebook (*M* = 3.71, *SD* = .96), *t* = -4.08, *p* = 5.82E-05.

Hypothesis two stated that rare disease patients, parents, and caregivers will use the information found on social media in conjunction with their physician’s recommendations. This hypothesis was not supported. The results from a correlation test showed no significant relationship between seeking Facebook or Instagram and seeking a physician, *r* = -.06, *p* = .29.

Hypothesis three predicted that rare disease patients, caregivers, and parents will feel more supported through online platforms rather than their medical team or physical support systems. This hypothesis was not supported. The results of an ANOVA test showed that perceived levels of support for social media (*M* = 3.33, *SD* = .75) were not significantly different than from their medical team (*M* = 3.25, *SD* = .85) and their friends and family (*M* = 3.22, *SD* = .85), *p* = .25.

Hypothesis four stated that the use of social media in rare disease patients, parents, and caregivers has a perceived positive impact on their level of mental health. This hypothesis was not supported. The results from a correlation test showed no significant relationship between social media use and perceived mental health levels, *r* = -.01, *p* = .89.

Hypothesis five predicted that patients, families, and caregivers will report awareness of treatments on social media. This hypothesis was supported. The results from a correlation test showed a significant relationship between social media use and awareness of treatments or therapies, *r* = .15, *p* = .01.

**Conclusion**

This research examined patients, parents, and caregivers’ use of social media for rare disease management, advocacy, and care to assist healthcare businesses and hospitals in their mission to meet patients’ needs. Due to the geographic spread and rarity of these conditions, this group of individuals needs unique care and support from the industry to increase their quality of life and access treatments, information, and therapies. The way healthcare businesses interact with this group will be altered by examining the relationship between rare disease patients, parents, and caregivers. The research questions used to traverse this research were:

1. What are the attitudes towards the medical information available on Facebook and Instagram support groups for rare diseases?
2. Will the patients, families, and caregivers feel more supported through social media support groups?
3. Do patients, families, caregivers, and professionals have better access to treatments/or promote treatments on social media?

After vast research on various facets encompassing rare diseases was conducted, two key findings were discovered and implemented into the survey for primary research. The first regarded medical information available on social media and the community's comfort with its use. From a medical perspective, Facebook has been shown to achieve patient needs more effectively due to its algorithm, structure, and policies (Gurler & Buyukceran, 2022). From conversations about medications that relieve adverse symptoms to outstanding clinical trials, treatments, and drugs, healthcare information is passed instantaneously daily (Lazard et al., 2021).

Moreover, the survey results focusing on information on Instagram versus Facebook support Gurler and Buyukceran’s findings. The results from the t-test in hypothesis one shows a significant difference in feelings between information found on Instagram and Facebook. Therefore, rare disease patients, parents, and caregivers prefer to see medical information on Facebook, as they reported a significantly higher likelihood of using that platform for medical care.

The second finding from this research was that social media is a place of primary contact between patients and businesses that can provide new therapies or politicians who lobby for new policies (Miller et al., 2021). The results from a correlation test in hypothesis five showed a significant relationship between the use of social media and the awareness of treatments and therapies in rare disease patients, parents, and caregivers. These findings suggest that social media has made therapies, clinical trials, and treatments more accessible and increased awareness among consumers, as Miller et al. (2021) studied.

**Future Directions**

**Business Suggestions**

From a business standpoint there are multiple suggestions one could derive from both the secondary and primary research collected. One recommendation is for pharmaceutical companies, healthcare businesses, or hospital brands to post information about their products via Facebook. The feelings towards information on Facebook create an effective environment for these businesses to market their products and services.

The second suggestion is primarily for physicians but can be used for pharmaceutical companies. Since no significant relationship was found between seeking social media and seeking a physician, this could mean many things. First, doctors must be aware of individuals using social media for medical advice without consulting professionals, primarily paying extra attention to those who don’t ask for medical advice or assistance often due to the negative correlation. Secondly, pharmaceutical companies should be aware of the impact social media could have on patients, parents, and caregiver’s medical information intake. Ensuring that all posts and advertisements accurately represent the therapies and treatments they manufacture will ensure that they are reaching the right target group who are most likely to benefit. Social media is also an effective place to promote therapies and treatments, and healthcare businesses should utilize this space to grab consumers’ attention and build relationships.

Lastly, the third suggestion is for businesses in the healthcare sector to utilize social media platforms and collaborate with healthcare professionals to provide support to patients, parents, and caregivers. These companies can also assist with mental health services and support to create a customer-centric company and advertising strategy. This would increase loyalty, create a positive public image, and benefit patients by creating a more supportive space.

**Additional Research**

Further research with more diverse respondents is needed to provide a comprehensive understanding of social media's impact on rare disease patients, parents, and caregivers. Each of the 7,000 declared rare diseases have different lifestyles, struggles, research, funding, and more (National Organization for Rare Diseases, n.d.). Diversifying the participants by encompassing more rare diseases would better capture the population's behavior. Additionally, one could group participants by condition if consent and anonymity are maintained. This could reveal further analysis and breakdown between the rare conditions themselves.

Moreover, diversifying the respondent group by gaining more of an equal proportion within gender, location, and age could reveal further analysis opportunities. Drawing conclusions based on the comparison of ages, genders, locations, and rare diagnoses would better inform healthcare professionals about where each is getting medical information and support. It also would help businesses better target their desired consumers and overall help patients get the care they need.

Lastly, one could focus solely on social media, revealing what drives patients to feel connected and supported and ultimately trust what they see on social media. This could be used to create a specific outline of how healthcare businesses can best target and support this consumer group.

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**Appendix A.**

**A1: Survey of Patients, Parents, and Caregivers**

Start of Block: Qualification Questions

Welcome and thank you for your participation in the survey!  
  
As a part of Endicott College’s curriculum, Senior students must conduct a thesis on a specific topic. The following survey pertains to rare medical conditions and personal social media use.   
  
Your responses will be kept strictly confidential and no personally identifiable information will be shared or used for any other purpose than this survey. Responses from this survey will only be used for educational data analysis. The survey will take approximately 5 minutes to complete.

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| --- | --- |
| Page Break |  |

Q1 Please select which statement best describes you:

* I am a patient with a rare disorder. (1)
* I am a parent or caregiver of someone with a rare disorder. (2)
* I am a doctor or physician (3)
* None of the above (4)

Skip To: End of Survey If Please select which statement best describes you: = I am a doctor or physician

Skip To: End of Survey If Please select which statement best describes you: = None of the above

|  |  |
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Q2 How often do you use Facebook and/or Instagram (for social and informational support, research, and advocacy) related to rare disorder management or care?

* 1- Never (zero times) (1)
* 2- Sometimes (less than half) (2)
* 3- About half the time (3)
* 4- Frequently (more than half) (4)
* 5- Constantly (all of the time) (5)

Skip To: End of Survey If How often do you use Facebook and/or Instagram (for social and informational support, research, a... = 1- Never (zero times)

|  |  |
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Q3 Select the age range you reside in.

* Under 18 (1)
* 18 - 24 (2)
* 25 - 34 (3)
* 35 - 44 (4)
* 45 - 54 (5)
* 55 - 64 (6)
* 65 or older (7)

Skip To: End of Survey If Select the age range you reside in. = Under 18

End of Block: Qualification Questions

Start of Block: Hypotheses questions

Q4 Rate your feelings regarding information on Instagram related to your own medical condition or those you support's medical condition on a scale from 1 to 5:

* 1- I feel very negatively (1)
* 2- I feel somewhat negatively (2)
* 3- I feel neutral (3)
* 4- I feel somewhat positvely (4)
* 5- I feel very positively (5)

Q5 Rate your feelings of information on Facebook related to your own medical condition or those you support's medical condition on a scale from 1 to 5:

* 1- I feel very negatively (1)
* 2- I feel somewhat negatively (2)
* 3- I feel neutral (3)
* 4- I feel somewhat positvely (4)
* 5- I feel very positively (5)

Q6 Rank your frequency of seeking a physician when you have questions about your own rare disorder or those you support's rare disorder:

* 1- Never (1)
* 2- Sometimes (2)
* 3- About half the time (3)
* 4- Most of the time (4)
* 5- Every time (5)

|  |  |
| --- | --- |
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Q7 Please rank your likelihood of checking Facebook and Instagram when you have questions about your own rare disorder or those you support's rare disorder.

* 1- Never (1)
* 2- Sometimes (2)
* 3- About half the time (3)
* 4- Most of the time (4)
* 5- Every time (5)

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Q8 Please rank how supported you feel by each of the following:

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Very unsupported (1) | Somewhat unsupported (2) | Somewhat supported (3) | Very supported (4) |
| Your medical team (1) |  |  |  |  |
| Your immediate and extended family or friends (2) |  |  |  |  |
| Rare disorder social media support groups (3) |  |  |  |  |

Q9 How many days in the last month have you used social media for rare disorder medical needs? If you are unsure, give a rough estimate.

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | 0 | 3 | 6 | 9 | 12 | 16 | 19 | 22 | 25 | 28 | 31 |

|  |  |
| --- | --- |
| None () |  |

Q10 Within the last month, how would you rate your overall mental health level?

* 1- Poor (1)
* 2- Somewhat poor (2)
* 3- Average (3)
* 4- Somewhat good (4)
* 5- Good (5)

Q11 Please rank your awareness of treatments or therapies available for your own condition or those you support's condition on Facebook and Instagram.

* 1- Not aware (1)
* 2- Slightly aware (2)
* 3- Moderately aware (3)
* 4- Very aware (4)
* 5- Extremely aware (5)

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End of Block: Hypotheses questions

Start of Block: Demographics

Q12 Please select your gender.

* Male (1)
* Female (2)
* Non-binary / third gender (3)
* Prefer not to say (4)

Q13 Where is your primary residence located?

* North America (1)
* Europe (2)
* Australia (3)
* South America (4)
* Asia (5)
* Africa (6)
* Oceania (7)

End of Block: Demographics