Journal of Ecohumanism
2024
Volume: 3, No: 8, pp. 12202 – 12212
ISSN: 2752-6798 (Print) | ISSN 2752-6801 (Online)
https://ecohumanism.co.uk/joe/ecohumanism
DOI: https://doi.org/10.62754/joe.v3i8.5824

Analytical Review of Awareness about Rare Diseases Among Sharjah University Students

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Abstract

Individuals with rare disabilities face several challenges, such as isolation, stigma, discrimination, and fewer educational and employment opportunities. Few studies have examined individuals' knowledge regarding rare disabilities in the Emirati context. This study aimed to identify the level of awareness about rare diseases among Emirati students. A total sample of 200 students was recruited as participants from the University of Sharjah self-administrative questionnaire was distributed to collect primary data and to examine the level of general knowledge of rare diseases to identify the extent of Emirati society's awareness of these disabilities and the necessary therapeutic interventions. Our findings revealed that the participants had low awareness of rare diseases in the Emirati context. Furthermore, statistically significant differences were found between the level of awareness of rare diseases and students' specialization. We recommend that more field visits to be conducted to expose the students at the university with the institutions that care for people with rare disabilities. Raising awareness around rare diseases and disabilities will help in integrating individuals with rare diseases into society. Although our study findings contribute to the literature on rare diseases and disabilities in the Emirati context, it also has important implications for policymakers.

Keywords: *Awareness, Rare Diseases, Disability, University of Sharjah, Therapeutic Interventions.*

Introduction

Increasing efforts are being directed toward improving the situation of individuals with rare diseases; however, the nature of these diseases and the different challenges they impose remain unclear, especially for families of individuals with such diseases (Huyard, 2009). According to European legislation, a disease or disorder is considered rare when it affects less than 5 per 2,000 people. The number of rare diseases recorded by official authorities is considerable, and the online international medicine database "Orphanet" currently includes around 15,000 rare diseases (Fabregat, Araujo, & Martinez-Romo, 2018). Many of these diseases are associated with disabilities. Therefore, it is important to know the development of the disease in advance to limit and prevent the occurrence of disabilities, improve the patient's environment, and provide adequate healthcare and community support to deal with the challenges and needs of their daily lives.

Rare diseases constitute a large and heterogeneous group of diagnoses, many of which cause chronic disabilities that have a significant impact on the lives of the affected individuals, their families, and the healthcare system. Each individual disorder is rare; however, when viewed as a group, rare disorders are fairly common, with an overall prevalence rate of approximately 6–8%. Kvarnung and Nordgren (2017) revealed that the clinical presentation of these disorders includes a wide range of signs and symptoms, leading to mental disabilities, neuropsychiatric disorders, epilepsy, and kinetic disorders.

A rare disease is defined as a disease with a prevalence of less than 1/2000; in the United States of America, it affects less than 200,000 people, and in Australia, it has a prevalence of 1/10,000. There are approximately 8,000 rare diseases worldwide, which collectively affect approximately 6–10% of the global population. This equates to 30 million, 25 million, and 1.2 million individuals in Europe, the United States of America, and Australia, respectively.

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In comparison, diabetes affects an estimated 20.8 million people in the United States of America and 1.4 million individuals in Australia. It is increasingly recognized that the low rate of spread of a disease does not imply a decrease in effect; however, there is no empirical and scientific data for many rare diseases. Rare diseases often begin in childhood, and they continue throughout life, inhabit or threaten life, and are difficult to diagnose. Most of them have no cure, but a few scholars have examined their effects on individuals, health professionals, healthcare services, and the community (Zurynski, Frith, Leonard, & Elliott, 2008).

Individuals with rare disabilities face isolation, stigma, and discrimination and have lower access to educational and employment opportunities. It should be noted that at least half of the rare diseases begin in childhood, and for many children, education is either disrupted or becomes unfeasible. This is owing to the differences in challenges and difficulties depending on the type of disability. Those with Rett Syndrome, a rare genetic neurological disorder that almost exclusively affects females, have difficulty accessing appropriate education (Dellve, Samuelsson, Tallborn, Fasth, & Hallberg, 2006).

The UAE guarantees equality to people of determination (people with disabilities or those with special needs) through its legislation, as well as economic and social development programs and policies. Federal protects the rights of people of determination and guarantees them the right to live with dignity. According to the law, a person's special needs shall not be a reason to deprive him/her of their rights and services, especially in welfare as well as social, economic, health, educational, professional, cultural, and leisure services. The UAE has made big efforts to include people of determination in mainstream educational settings.

The UAE provides equal and fair employment opportunities to Emiratis of determination. UAE nationals with special needs have the right to work and occupy public positions. People of determination are entitled to receive monthly assistance subject to terms as per the existing laws. Resolution No. 43 of 2018 in support of the people of determination aims to support the rights of people of determination (people with special needs or disabilities) in the field of employment by enabling access to opportunities in the labor market. The resolution requires government entities to protect the rights of people of determination and to ensure their right to work on an equal basis with others and not to be discriminated against. It has guaranteed the rights of people with rare disabilities among the general disabilities in Emirati society. The laws and legislation for this category come within the legislation for disabilities in general

A society that deals with such cases must have a certain degree of awareness and sufficient knowledge about these rare diseases. Therefore, the current study aimed to perform a sociological analysis to examine the levels of knowledge and awareness among a sample of members of Emirati society. The following two research questions were formulated:

- What is the extent of knowledge in Emirati society regarding rare diseases?
- What is the extent of knowledge in Emirati society about the types of therapeutic interventions provided for individuals with rare diseases?

Regarding the actual spread of these rare diseases, several studies have highlighted the importance of constant changes at the global level because of the continuous diagnosis of these diseases and continual therapeutic and community interventions. A gradual increase in prevalence rates and insufficient diagnostic and treatment methods is observed, which leads to scientific and cognitive contradictions between the progress in cases and those that are not recorded and the numbers that are published (Auvin, Irwin, Abi-Aad, & Battersby, 2018).

Treatable diseases can significantly enhance health outcomes and reduce the burden on patients, their families, and society. For rare diseases, which is an area in which financial and scientific resources are particularly scarce, web application technology aimed at raising awareness of such diseases and exploring the possibility of improving health outcomes has been developed (van Karnebeek, Houben, Lafek, Giannasi, & Stockler, 2012).

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Providing timely, molecularly confirmed diagnosis for children and adults with rare genetic diseases reduces their "under-diagnosed rare disabilities." Genetic counseling regarding the risk of disease recurrence ensures reproductive safety, as the current global diagnosis rate is approximately 50%. However, for those who do not receive a diagnosis after an initial genetic evaluation, this rate is much lower. Undoubtedly, further research efforts are needed to obtain a more comprehensive list of genes and variants associated with various diseases. The Rare Disease Research Consortium was established in 2011 to promote international collaboration among scholars and organizations that are active in rare diseases research. Boycott et al. (2017) suggested that research is critical to develop a means to achieve molecular diagnosis for all rare diseases.

Several studies have highlighted the systemic challenges associated with aging, health, and mortality in adults with rare disabilities. A few studies conducted in this area have highlighted certain limitations, such as the inability to ensure that older people have a genetic diagnosis as opposed to a clinical diagnosis and the possibility that adults may not receive adequate healthcare facilities and referral to genetics specialists. Aging in Prader-Willi and Williams syndromes is being examined because it offers new insight into the phenotypic treatment of older adults with these disorders (Dykens, 2013).

In the context of the awareness of differences and stigma among people with intellectual disabilities, the extant literature indicates that it is largely social, considering the medical aspects, and is rarely linked to developmental perspectives. Studies have concluded that it is necessary to promote awareness in society about these rare disabilities, with no direct positive correlation among gender, age, and experience. Furthermore, general societal awareness must be fostered among all age groups. However, children under the age of eight require special programs because of the comparisons that they form at a young age with their peers, especially due to Duane syndrome (Cunningham & Glenn, 2004).

Considerable efforts are being made to improve the condition of individuals with rare diseases; however, the specific nature of these disorders remains unclear. Studies have revealed a number of situations that people with rare disorders are exposed to, which they consider to be unjust and caused by their disabilities. Huyard (2009) reported that they attribute these challenges to a lack of awareness and adequate support from medical practitioners and local communities; their high ethical expectations toward medical care providers and the general societal context creates gaps and difficulties in different situations.

Several factors affect access to healthcare among persons with disabilities, such as the attitude of healthcare providers and the public, physical barriers, misunderstanding, income level, racial/minority status, insurance coverage, and lack of information specific to persons with disabilities. Sharby, Martire, and Iversen (2015) revealed that either service providers are uninterested or people with rare disabilities are sensitive to their own needs and unlikely to seek suitable care or follow-up. Multiple strategies must be developed to improve medical facilities and change the manner in which individuals access healthcare services.

Patients with disabilities often receive unequal medical and social care. In addition, mothers feel that their children affected by rare diseases do not have adequate access to appropriate healthcare services (Sharby et al., 2015).

Although rare disabilities have a low prevalence rate and collectively affect 6–10% of the global population, they have a significant impact on patients and their families, healthcare services, clinicians, and the wider community. Accurate data are needed to guide clinical practice, government policy, and healthcare resources. A lack of a national approach to address these disabilities and to support research, promote advocacy, and equitable access to healthcare for children with rare diseases is observed (Zurynski et al., 2008).

Living with a child with a disability has profound implications for the entire family. With the prevalence rate of rare disabilities being approximately 2.5%, there is an urgent need to promote enhancements in the global healthcare system. Little is known about the changes and adaptations made by affected families, and this scarcity of information hinders the improvement of services. Studies have revealed that individuals are generally satisfied with the services provided for diagnosis and follow-up, relationship with the family pediatrician, and rehabilitation services and schools regardless of the severity of the condition, presence of intellectual disability, or absence of a diagnosis (Silibello et al., 2016).

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The situation in Australia is not a favorable one; approximately 8% of Australia's population is affected by around 10,000 rare illnesses. This number is similar to the percentage of individuals with diabetes or asthma. People with rare diseases face major challenges, including delays in diagnosis and treatment and difficulty in finding appropriate healthcare services. Families feel isolated, lack support, and often face economic difficulties. All general doctors who examine people with rare diseases play a decisive role in providing appropriate referrals, coordinating care, supporting families, and ensuring psychological, social, and other forms of support. Generally, doctors need to access their current resources to help patients with rare diseases (Elliott & Zurynski, 2015).

A closer look at the number of families reported for each of the non-multifactorial disorders, whereby all related individuals count as a single family, expectedly highlights disorders such as Cystic Fibrosis (219700), Beta-Thalassemia (613985), and Sickle Cell Anemia (603903), which have been reported in at least 30 unrelated Emirati families and shown to be highly prevalent in the UAE (Elsaban, Ahmad, Toba, Alsaeed, & Abusalah, 2021). In the GCC exactly in Bahrain, there was a weak correlation between self-declared knowledge and the overall score achieved ($r=0.190$; $p<0.001$), which indicates that the population's self-declared knowledge did not portray their actual knowledge of rare diseases (Sinan, Mihdawi, Farahat, & Fida, 2023).

Protic et al. (2021) highlighted that medical students in Serbia, Georgia, and Colombia lack sufficient knowledge of noninfectious diseases during the university stage and that their training in this area must be more rigorous. Furthermore, the presence of a large gap in knowledge about Fragile X syndrome among senior medical students in these developing countries is rather evident. Information on such diseases can be partially circulated to other developing countries to increase knowledge and awareness of noninfectious diseases and enhance institutional cooperation between developed and developing countries (Protic et al., 2021).

Methodology

This is a cross-sectional study regarding knowledge about rare diseases. Data were collected at the University of Sharjah, United Arab Emirates between August 2023 and December 2023. A total of 200 students out of 19,246 were determined, and the specialization and sample size were determined by random sampling and acceptance to participate in the study. The survey was designed based on the comments of three sociology and public health experts and a review of the literature from 30 different databases. The internal consistency of ($\alpha = 0.79$ and 0.74, respectively).

The survey was conducted using random sampling. The questionnaire was distributed to 300 students, with a response rate of 250 questionnaires, and 50 of them were excluded for not meeting the conditions.

The questionnaire with distributed to the participants via email to students from the following specializations at the University of Sharjah: Arts and Humanities, Communication, Law and Shari'a, and Medicine. The participants were invited to complete a voluntary anonymous online self-administrative questionnaire (Google Forms). At the end of the first part of the electronic questionnaire, two options were generated: "I agree to participate in the study," and "I do not wish to participate in the study." Participants who chose the second option were excluded. Informed consent was obtained from all the study participants.

The survey consisted of 18 questions, which were divided into three sections. The first section comprised the socio-demographic characteristics.

The second part included items on the general knowledge of rare diseases among members of Emirati society, which aimed to determine their awareness level of these disabilities. The third section assessed the extent of awareness and knowledge in Emirati society regarding the type of support provided to individuals with rare diseases and its proportionality to the reality of society. This section contained four questions to evaluate practical knowledge of therapeutic interventions and support in the United Arab Emirates. For example, participants were asked to share their opinions on the best way to provide support to people with rare disabilities in the Emirates.

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Ethical Approval

The Ethics Committee of the University approved this study (grant number: REC-24-03-27-02-F). An information page that explained the study objectives and research procedures was provided along with the questionnaire.

Statistical Analysis

Statistical analysis was performed using IBM SPSS Statistics 22 (Version 2022, licensed and permitted by the University of Sharjah). Data was analyzed using the descriptive using the simple analytical statistics' repetition and proportions of nominal variables. In addition, we used scales of dispersion, with a focus on the standard and medium-arithmetic deviation to determine participants' knowledge level regarding various rare diseases. The results were categorized by gender to understand gender differences and their impact on the knowledge of members of Emirati society. Percentages and chi-square tests were used for binary and categorical variables $p<0.05$ indicating statistical significance and Means, standard deviations (SD), and min-max were used for continuous variables. is rare diseases in Emirati society were defined as independent variables and awareness about the rare diseases represents the dependent variable.

Results

This study included participants from different age groups, with the largest group comprising individuals aged 19–20 years (40%). This was followed by participants aged 21–23 years (30%) and those aged 24 years and above (29%).

In terms of gender distribution, more than half of the participants were female (63%) while 37% were male. When considering the academic status, the majority of participants were first-year students (43%), followed by second-year students (36%). Third-year students accounted for 14% of the participants while the smallest group comprised fourth-year students (5%).

Regarding awareness about health-related topics, the majority of participants (88%) were not familiar with the concept of chronic diseases in general. Additionally, a smaller proportion of participants (approximately 23%) had knowledge of the term "rare diseases." Table 1 presents the data.

[Table 1 near here].

[Table 2 near here].

Table 2 indicates that the research participants had a positive attitude toward their overall knowledge of rare diseases, with an average score of 2.39 and 1.8 for their understanding of rare disabilities and therapeutic approaches for individuals with rare diseases, respectively.

[Table 3 near here].

Table 3 indicates the general knowledge of students at the University of Sharjah regarding rare diseases, their relationship to the students' specialization, and the presence of statistical significance (mutual effect) between the awareness of a specific disease and the university specialization.

Findings suggest that medical students showed the highest level of general awareness, as indicated by the higher percentage of correct answers (Agree or Strongly Agree). The specializations with the highest scores were Shari'a, Communication, and Arts and Humanities.

Among the most well-known rare diseases, the majority of the participants were aware of Down syndrome. The percentage of students who confirmed their knowledge about this genetic disorder was 42% for the College of Medicine, followed by the College of Communication (75%); the College of Arts, Humanities, and Social Sciences (50%); and the College of Shari'a. Another disease mentioned was "xx," where the

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College of Medicine (n=108) had the highest number of correct answers, followed by the College of Arts, Humanities, and Social Sciences (n=42); College of Communication (n=33); and the College of Shari'a (n=19).

Furthermore, the analysis revealed a statistically significant relationship between the specialization and the general knowledge of diseases, particularly for Cornelia de Lange syndrome (p=0.03), Kabuki syndrome (p=0.05), Down syndrome (p=0.01), and progeria (p=0.05).

[Table 4 near here].

Table 2 shows the general knowledge of University of Sharjah students about therapeutic interventions and medical support for people with rare disabilities and the specialization to which the student belongs, and the presence of statistical significance (mutual effect) between knowledge and awareness of therapeutic interventions and university specialization.

The results reveal the presence of general awareness among medical students because of specialization and knowledge, as they obtained the highest correct answers (Agree - Strongly Agree) for the specialty of Sharia, Communication, and Arts, followed by the College of Arts, Humanities, and Social Sciences, then the College of Communication, and then the College of Sharia.

It was also shown that there was a high level of support for the establishment of therapeutic clinics that care and provide medical support for this group in society, as confirmed by (50%) of medical students, (28%) of art students, (33%) of communication students, and (1%) of Sharia students. The majority of them also support the presence of full support for this group in Emirati society (40%) of medical students, (5%) of communication students, (12.5%) of arts students, and (2) of communication students.

The results show that there is a statistically significant relationship between knowledge of therapeutic interventions and the importance of having clinics that care and care for this group (P=0.001.). It also shows that there is a statistically significant relationship between knowledge of the type of health support provided and general knowledge of therapeutic interventions (P=0.001).

Discussion

This study aimed to examine the awareness levels of 200 Emirati students regarding rare disabilities using an online self-questionnaire. Participants were primarily young adults from the University of Sharjah majoring in Communication, Arts and Humanities, Medicine, and Law and Shari'a. In general, the participants were first- and second-year students who had basic general knowledge about rare diseases. Most of the participants did not have awareness about these diseases compared with less than one-third of the sample who had some idea about them.

Our study identified a low level of awareness of rare diseases in Emirati society. However, the level of knowledge about some diseases, such as Fragile X and Down syndrome, was high. Participants had clear perceptions of the importance of providing medical support and establishing special treatment clinics for this category. They did not support the isolation and non-integration of people with rare diseases into society. Findings revealed that the specialization as well as the ideological and cognitive backgrounds of the students influenced the level of general knowledge about rare diseases, disabilities, and therapeutic interventions in Emirati society.

Although the idea of rare diseases has gained rapid and widespread legal and international recognition (Winance & Barral, 2013), there is a need to promote awareness about rare disabilities (Cunningham & Glenn, 2004). However, public awareness and average levels of knowledge about these rare disabilities and therapeutic interventions remain ineffective along with medical and legal efforts in Emirati society toward this area.

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Considerable efforts to improve the situation of people with rare diseases are being made. However, knowledge and education are crucial, as they play a major role in reducing the severity of situations to which people with rare disorders are exposed that they consider unfair, primarily due to a lack of awareness and inadequate support from practitioners. Both medical and local communities, with expectations toward the general societal context, create gaps and difficulties in different situations (Huyard, 2009). It is expected that university students, especially medical students in the third and fourth years, will be more knowledgeable about these diseases such that they can contribute to raising the awareness level of the community.

Individuals who are afflicted with Kabuki syndrome, cat cry syndrome, and fish skin disease receive poor medical and social care (Sharby et al., 2015). Despite the medical efforts and establishment of public benefits associations in Emirati society, there is a need to improve medical awareness to raise the levels of knowledge and provide adequate support to people with rare diseases.

The study findings conform to the results of Protic et al.'s (2021) study, which reported on the insufficient knowledge about noncommunicable diseases among university students in Serbia, Georgia, and Colombia. People's knowledge about this field should be more intensive. In addition, a large gap in knowledge regarding Fragile X syndrome was observed among senior medical students in these three developing countries. The findings of the present study can be partially generalized to other developing countries to increase knowledge and awareness of noncommunicable diseases and strengthen institutional cooperation between developed and developing countries (Protic et al., 2021). Such efforts will help to raise awareness and increase the sense of societal responsibility among various countries toward rare disabilities and reduce the burden on affected individuals, medical personnel, and families.

Conclusion

Results indicated that participants had a weak level of knowledge in general. An increase in knowledge about several rare disabilities was observed, which may be due to the extent of the prevalence of these diseases in Emirati society, as Down syndrome is the most common disability in the Emirates.

There is a close relationship between the course specialization, its focus area, and the subjects of its study and between the knowledge of rare diseases and therapeutic interventions to deal with them in the context of Emirati society. This indicates the importance of society and medical culture in addition to the scientific ideological background of the specialty, which international universities should focus on. General knowledge about rare disabilities was extremely low, as only 11% of the study participants confirmed that they had previously heard or knew about these type of diseases before participating in the study. This emphasizes the importance of conducting studies and field visits to institutions that care for people with rare disabilities.

The support provided to individuals living with rare disabilities in Emirati society is high, developed, and diverse. However, there is a gap between what the state offers and seeks and the knowledge of the members of society, especially young adults in theoretical disciplines. It is crucial to raise awareness of rare diseases and seek ways to integrate individuals with such disabilities into society. The study findings have valuable implications for policymakers and developing nations who want to promote awareness of rare diseases among citizens.

Practical Recommendations

Raising awareness about this type of disability in the local community and the university.

Increasing research on "difficulties of integration, acceptance and awareness" in society towards people with rare disabilities.

Developing special legislation for people with rare disabilities comes within the legislation for people with disabilities in general to ensure their integration and awareness of their disease.

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Finding ways of cooperation between universities and people with these disabilities through clear policies to raise awareness of their conditions and their methods of therapeutic intervention.

Acknowledgements

[We thank SAGE Author Services for the help with proofreading and pre-publication instructions.].

Authors' Contributions

All authors have read and agreed to the published version of the manuscript.

Funding

This research received no external funding.

Institutional Review Board Statement

The Ethics Committee of the University of Sharjah approved this study (grant number: REC-24-03-27-02-F). An information page that explained the study objectives and research procedures was provided along with the questionnaire.

Conflicts of Interest

The authors declare no conflicts of interest.

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Table 1. Characteristics of the Participants

	N	%
Age (in years)		
19–20	80	40
21–23	61	30.5
Above 24	59	29.5
Gender		
Male	76	37
Female	126	63
Academic year		
First year	87	43.5
Second year	73	36.5
Third year	29	14.5
Fourth year	11	5.5
Do you know the term "rare diseases?"		
Yes	23	11.5
No	177	88.2

Table 2. General Knowledge of Rare Diseases Versus Therapeutic Interventions

	Mean X±ss	Min–max
General knowledge of rare disabilities among young people in Emirati society	1.413±0.814	0.1–3.1
Awareness of therapeutic interventions for rare disabilities	1.079±0.353	0.0–1.8

Journal of Ecohumanism
2024
Volume: 3, No: 8, pp. 12202 – 12212
ISSN: 2752-6798 (Print) | ISSN 2752-6801 (Online)
https://ecohumanism.co.uk/joe/ecohumanism
DOI: https://doi.org/10.62754/joe.v3i8.5824

Table 3. Participants' Self-Assessment of Their Knowledge Regarding Rare Diseases as Per the Students' Specialization; Responses, N (%).

Items	Arts and Humanities	Communication	Law and Shari'a	Medicine	χ^2	p
Extremely knowledgeable about Cornelia de Lange syndrome	12 (6)	16 (8)	5 (2.5)	20 (10)	11.26	0.003*
I understand what Wolf-Hirschhon syndrome is	8 (4)	10 (5)	6 (3)	15 (7.5)	0.02	0.926
Knowledge about FXS or Fragile X syndrome (this condition is the most prevalent hereditary cause of mental disease)	42 (21)	33 (16.5)	19 (9.5)	108 (54)	2.61	0.271
I am familiar with cat cry syndrome	3 (1.5)	2 (1)	1 (0.5)	10 (5)	5.04	0.080
I am aware of Kabuki syndrome	4 (2)	1 (0.5)	4 (2)	7 (3.5)	49.17	<.0001*
I am aware of Patau syndrome	9 (4.5)	4 (1.15)	2 (1)	10 (5)	4.84	0.089
I am aware of progeria syndrome (premature aging)	10 (5)	1 (0.5)	1 (0.5)	7 (3.5)	10.60	0.005*
I am aware of Angelman syndrome	11 (5.5)	5 (2.5)	3 (1.5)	13 (6.5)	3.14	0.208
I am aware of Duane syndrome	50 (25)	75 (37.5)	33 (16.5)	85 (42.5)	45.65	<.0001
Average general knowledge	2.28					

Note: χ^2: value of Chi-square test; *statistically significant p value: $p<0.05$.

Table 4. Participants' Self-Assessment of Their Knowledge of the Medical Support Provided to Individuals with Rare Disabilities as the Students' Specialization; Responses, N (%).

Items	Arts and Humanities	Communication	Law and Shari'a	Medicine	χ^2	p
Knowledge regarding the appropriate ways to deal with blood disorders to promote awareness in Emirati society	25 (12.5)	10 (5)	3 (1.5)	80 (40)	11.26	0.013
Treatment centers for people with rare disabilities must be established	56 (28)	33 (16.5)	2 (1)	100 (50)	1.49	<.0001*
I know the type of counseling support	1 (0.5)	13 (6.5)	1 (0.5)	8 (4)	4.74	<.0001*

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required for people with blood disorders in the Emirati community						
Such individuals must be ignored	4 (2)	4 (2)	1 (0.5)	8 (10)	2.91	0.23
Average general knowledge	1.97					

Note: χ^2: value of Chi-square test; *statistically significant p value: $p<0.05$.