

Quality of Life and Academic Experiences of Students with Visual Impairments

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Key words: Blindness, disability, focus group, low vision, accessibility

Abstract: The aim was to investigate the effects of Visual Impairments (VIs) on the Quality of Life (QoL) of students with low vision and blindness at the University of Jordan and to explore their academic experiences. Mixed research methodologies were used. In the quantitative part, a cross-sectional design was incorporated. The sample comprised 40 students with visual impairments and completed the (NEI-VFQ-25) questionnaire. In the qualitative part 6 students were audio taped during a focus group interview. The SPSS Version 22.0 (2016, IBM Corporation, New York) was used to analyze data of the quantitative stage. The thematic content analysis was used in analyzing the qualitative data. The average of the composite score in the NEI-VFQ-25 of the total sample was 60.18 ± 12.83 and ranged between 25.63-96.08 out of 100. The highest mean score in the 12 subscales was for "general health" while the lowest mean score was for "general vision". The major themes from the thematic content analysis were "the effects of the support system", "academic challenges and barriers" and "levels of satisfaction and QoL". Findings suggested that students with VIs had an average perception of QoL in their daily life activities and lower levels of QoL in academic experiences.

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INTRODUCTION

Visual Impairments (VIs) are health conditions that have major social and economic effects particularly in developing countries^[1, 2]. VIs result in several negative consequences on participation in meaningful occupations and the sense of health and well-being^[3, 4].

Several aspects of life are negatively affected by VIs including, education, functional activities and participation in social and familial activities^[5]. Several studies found that people with severe VIs are at higher risk of developing stress and depression and their life-satisfaction is lower than people with no or mild levels of visual loss^[6].

The measurement of visual acuity or the visual field does not accurately reflect the degree of disability and the resultant restriction in participation in meaningful activities as experienced by People with Visual Impairments (PWVIs)^[7, 8]. The World Health Organization^[9] defined Quality of Life (QoL) as "the individual's perception of their lives within their sociocultural context and value system and as they conceptualize their goals, standards, expectations and concerns". The investigation of the perception of the QoL among PWVIs can be used to understand the degree and way in which the VIs affect the individual's life and participation in meaningful occupations^[10-13].

The National Eye Institute-Visual Function Questionnaire-25 (NEI-VFQ-25) (Version 2000) is an example of a self-reported assessment tool that is commonly used to measure the perception of vision-related QoL^[11]. It was first developed by Mangione *et al.*^[14] to measure the impact of VIs on health and QoL of PWVIs. The NEI VFQ-25, consists of 25 questions distributed across 12 subscales. Eleven of the twelve subscales are vision-related (general vision, near vision, distance vision, social functioning, role difficulties, dependency, mental health, driving, peripheral vision, color vision and ocular pain) and there is one general health related subscale. The final score of the NEI VFQ-25 ranges from 0 (lowest perception of QoL)-100 (highest perception of QoL)^[14].

The psychometric properties of NEI VFQ-25 are strong and yields valid data when used with visual conditions of various levels of severity^[14]. The NEI VFQ-25 has been translated and validated in different languages such as Italian^[15], Japanese^[16] and Arabic^[17].

Aims of the study: VIs affect the academic performance of PWVIs. Jorgensen *et al.*^[18] compared the academic performance between students with disabilities (including VIs) and students without disabilities for >12 years. They found that both groups had the same grades and academic outcomes but students with disabilities took lighter course loads and needed almost one semester longer to graduate. The impact of VIs in rehabilitation and special education are amongst the least researched topics of disabilities in Jordan^[19]. Currently, there have been only limited research studies conducted to investigate the impact of VIs on student's QoL in academic settings in Jordan. Hadidi and Al Khateeb^[19] reported on 169 students (90 students with blindness and 79 sighted students) from different schools and universities in Amman. It was found that students with blindness reported higher degrees of loneliness compared to sighted students.

The aim of the current study was to investigate the impact of VIs on the QoL of students with VIs at the University of Jordan and the effect of the academic context on their academic experiences. An objective of this study was to compare the results of this study with other studies conducted in different cultural contexts.

MATERIALS AND METHODS

This study received ethical approval from the deanship of scientific research at the University of Jordan. The study consisted of two stages that incorporated both quantitative and qualitative research methodologies to increase the credibility of the findings^[20]. The quantitative stage incorporated a cross-sectional design and a survey approach. The second qualitative stage was guided by the principles of the phenomenological approach^[21] and a focus group was employed as the method of data collection.

Participants were students with VIs from all educational levels and schools at the University of Jordan. They were required to be adults (≥ 18 years) and to provide their informed consent to participate. Convenience and snow-ball sampling were the methods of sampling employed in this study. Participants were first approached through the Department of Student Counseling at the deanship of student affairs at the university. The head of the department communicated with potential participants and invited them to participate in this study after providing them with information about the study. Students interested in taking part were provided with the principle investigator's contact details for further detailed information. The researchers explained the aims and information about the study's procedure and its benefits when they met with the participants. Participants were also encouraged to ask questions prior to providing their informed consent to participate.

In the first quantitative part of the research, the Arabic interviewer-administered version of the NEI-VFQ-25 questionnaire developed by Abdelfattah *et al.*^[17] was used.

Participants were asked to voluntarily provide their contact details if they were willing to participate in the prospective focus group. Participants who provided their contact details were contacted for the second stage. After conducting a preliminary analysis of the results of the first questionnaire-stage, a focus group was conducted. About 6-8 participants in the focus groups was considered as sufficient to elicit the necessary interactions to generate in-depth data^[22].

The focus group aimed to explore the experiences and perceptions of participants of their QoLs and academic experiences. Furthermore, earlier preliminary results from the NEI-VFQ-25 questionnaire stage were presented to participants where they provided their own reflections and elaborated on their experiences. A topic guide included questions that served as pointers to guide the conduction and moderation of discussion at the focus group. Examples of questions were: 'How can you describe the level of your QoL at the university?', 'What are the assets and challenges that influence your academic experiences at the university?' and 'What do you suggest to improve the QoL and academic experiences of students with VIs at the university?'. The focus group was recorded and then transcribed to perform analysis.

The SPSS Version 22.0 (2016, IBM Corporation, New York) was used to conduct descriptive statistics and report on the occurrence of categorical variables in the quantitative stage. When analyzing the qualitative data from the focus group, the researchers first familiarized themselves with the data by iteratively reading and re-reading the transcripts. A thematic content analysis was

used in analyzing data by categorizing all the statements that share the same meaning, condensing them into shorter forms and sorting them out using a system of codes. Relevant and interrelated codes were collated under main/core themes after searching for interrelations and associations.

RESULTS AND DISCUSSION

Total number of participants in the first stage was 40, males (n = 16), females (n = 24) with a mean age of 21±4.6 years, age range 18-46 years. Demographics of participants are presented in Table 1.

The mean total composite score of participants in the NEI-VFQ-25 was 60.18±12.83 which ranged from 25.63- 96.08 out of 100. The lowest composite score was for students who had associated diseases with VIs. Means of subscale and total composite scores of participants are presented in Fig. 1.

Six participants, two males and four females, age (mean 21.20± 3.10, range 19-27) had participated in the focus group. Table 2 presents the demographics of participants in the focus group. Data analysis of the qualitative data yielded four major themes and five of subthemes as shown below. Those themes are subsequently presented as subtitles.

The support system: This theme presented sources of support that students with VIs reported receiving at the university whether from formal or informal levels. The sources of support were mainly related to regulations established by the university to serve students with disabilities. The other source was related to provision of physical adaptations, assistive materials and technological resources.

Regulations: The students mentioned that the university has established regulations to facilitate the engagement of students with VIs in academic life. The first regulation that got the consensus of all participants is that they can register for courses before sighted students as M said, “we can register before the other students do”. In addition, the allowed time for students with VIs to complete the registration is longer by (4 h) than that allocated for sighted students (30 min). Another regulation was that students with VIs were allowed to record the lectures delivered by instructors “students with VIs are granted the formal permission from the deanship of students affair to record lectures” M said. During written exams students with VIs were allowed to have an extra half an hour of time and an extra of (50%) of the original time set for online exams and the university assigns a person from the deanship of student affairs to read exams for students with VIs, “students from different schools are assigned by the deanship for student’s affairs to assist us in taking the exams by reading questions and registering our answers” O said.

Technology and tools and adaptations: Students acknowledged that the availability of technological resources and tools helped them in their education. For example, there were magnifiers available to use in the main library, screen reader software in the computer lab

Table 1: Demographics of participants

Independent variable/subgroups	N (%)
Gender	
Male	16 (40)
Female	24 (60)
Visual status	
Low vision	19 (47.5)
Blind	21 (52.5)
Associated diseases	
Yes	3 (7.5)
No	37 (92.5)

N = Number of participants; (%) = Percentage

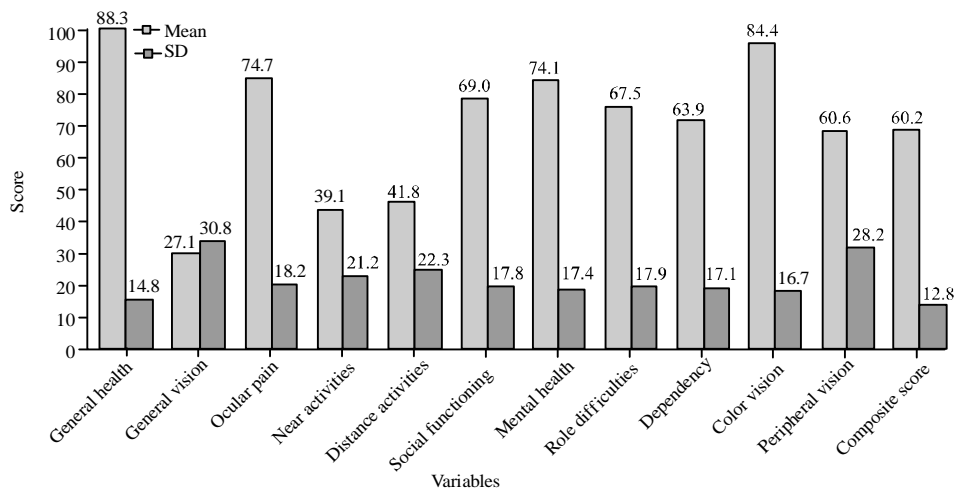


Fig. 1: Means and Standard Deviations (SDs) of NEI VFQ-25

Table 2: Demographics of participants in the focus group

Participant's identifier	Age	Gender	Visual status	Educational level	Schools
R	19	Female	Blind	First year	Arts
H	19	Female	Blind	First year	Educational sciences
A	19	Female	Blind	First year	Educational sciences
O	21	Male	Blind	Third year	Shari'a
S	22	Female	Blind	Third year	Foreign languages
M	27	Male	Low vision	First year	Rehabilitation sciences

at the deanship of student's affair, several textbooks in audio formats, textbooks printed in Braille and a Braille printer. In addition, for every student with VI there was an allowance of papers printed in Braille for each student. R mentioned that "there are many voluntarily initiatives conducted by other students inside the university to assist in the provision of main textbooks as audios". Moreover, the university constructed tactile indicator tiles to lead students with VIs between the schools and to protect them from hazards. As A and H said, "before we had the tactile indicator tiles, we could not move around without the help of other students, otherwise we either ended up stumbling with something or getting lost and never finding our way."

Challenges and barriers: The challenges and the barriers that participants faced in their academic context were categorized into: limited accessibility to academic resources, attitudinal barriers and physical barriers.

Limited accessibility to academic resources: Although, books printed in Braille were available, students reported that they were unable to get hold of them in a timely manner which affected their academic achievements. A said "I had a low score in the midterm exam as i only managed to get hold of the required resource of the course after the date of the midterm exam had passed". Although, there were technological resources available at the university such as screen readers and magnifiers, these were only available at specific locations at the university and participants were unable to use them inside the classrooms as a reported "there is only one screen reader available in the deanship of student's affairs and we have to go there if we needed it". M stated "the magnifiers should be available in all of the school's libraries across the university. Even if i have my own magnifier, I should be provided with ones by the university and leave my own to use at home". Another barrier participants faced was that the assigned readers for exams were required to be from a different school to the student with VI. Assigned readers struggled in reading the professional terms associated with a different discipline/major than theirs. In addition, some exams included pictures and figures and the readers could not explain/read to examinees with VIs.

Attitudinal barriers: Participants also perceived that there were attitudinal barriers that limited the degree of

their integration and participation throughout their academic experiences. As some of instructors underestimated the abilities of students with VIs and considered students with VIs as dependent individuals who lacked sense of power and control, a stated "some lecturers believed that we need help from others all the time and some lectures give extra marks to students with VIs without any merit".

Many instructors lacked the knowledge and awareness concerning the needs and rights of students with VIs and appropriate ways to communicate with them. A, H and M stated "most of the problems that we face were caused by some instructor's unawareness of the regulations established for us at the university".

A said "some lecturers use signs/signals in their communication which obviously we cannot see. Once an instructor asked me to answer a question by pointing at me and saying (you answer please) while i did not figure out that i am the one he actually meant".

Physical barriers: Participants mentioned that the tactile indicator tiles facilitated their orientation and mobility inside the campus. However, still there were physical barriers faced by students with VIs such as the trees along side the side walk and the unpaved pedestrian paths between the various schools. Signs, maps and significant landmarks were not written in Braille inside and outside some of the university's buildings, R reported "while trying to find my way across classrooms, many times I got lost and was late to lectures".

Satisfaction and quality of life: When students were asked about their QoL and the level of satisfaction with their academic life and experiences at the university, participants perceived their quality of their academic experiences to be generally, low at the university as a reported, "okay the offered services increased my QoL but still my satisfaction is low and my QoL doesn't exceed 30%".

Recommendations from the focus group: Focus group participants introduced several recommendations to promote the academic experiences of students with VIs. One of those was to increase awareness and knowledge of both the instructors and students concerning conditions of VIs and ways of communication with PWVIs. As M said, "there should be workshops conducted for instructors

Table 3: Scores of 12 subscales and composite score of this study and other studies

Variables	Abdelfattah <i>et al.</i> ^[17]	Mangione <i>et al.</i> ^[14]	Suzukamo <i>et al.</i> ^[16]	Gyawali <i>et al.</i> ^[23]	Current study
Demographic information from the source					
Country	Egypt	USA	Japan	Nepal	Jordan
Sample size (n)	379	528	243	44	40
Age (mean±SD)	54.50± 15.00	N/A	N/A	47.70±24.50	21.00±04.60
Subscale scores					
General health	57.30±03.10	53.50±06.65	45.40±01.70	36.90±21.90	88.25±14.80
General vision	48.90 ±06.70	60.00±13.50	53.30±11.00	39.10±18.80	27.10±30.80
Ocular pain	66.20±09.00	87.50±01.90	81.70±01.30	67.30±20.20	74.70±18.20
Near activities	42.90±07.90	64.80±17.80	57.00±16.20	47.40±18.90	39.07±21.15
Distance activities	50.88±06.10	65.66±16.60	54.10±12.40	47.30±18.90	41.75±22.27
Social functioning	73.75±07.10	79.30±16.30	69.90±12.20	53.70±17.90	68.96±17.80
Mental health	45.00±07.50	67.00±13.10	57.10±17.40	42.70±20.20	74.10±17.35
Role difficulties	53.56±08.70	68.66±14.40	61.00±19.66	42.90±26.50	67.50±17.90
Dependency	64.20±09.66	78.10±15.30	70.20±16.90	47.40±20.90	63.90±17.10
Driving	22.20±10.70	53.66±25.90	40.10±23.70	55.30±20.60	NA
Peripheral vision	67.95±06.60	75.80±09.10	59.40±04.00	77.30±25.20	60.60±28.20
Color vision	78.00±05.60	87.80±09.20	88.30±02.66	63.60±21.90	84.37±16.70
Composite score	58.80±05.30	NA	62.30±09.90	49.50±14.10	60.20±12.80

NA = Not Applicable

about students with disabilities to increase instructor’s awareness and knowledge concerning proper ways of communication with students with disabilities and their rights and regulations established to protect those rights”.

Another suggestion was to increase the resources needed by students with VIs such as Braille reader/note-taker, Braille printed papers, Braille printed books, provision of electronic version of the required courses’ materials. Participants also expressed that assistive and adaptive equipment, e.g., magnifiers and materials, need to be accessible by all students with VIs across all the university’s buildings and libraries. S stated, “Braille reader/note-taker need to be provided to students during the academic years,” M proceeded “such tools can be loaned/borrowed by students with VIs and after finishing their studies, students with VIs can return them back to the university”.

Participants also suggested the conduction of an orientation day to be organized for freshmen students with VIs to facilitate their ambulation at the university by familiarizing them with paths across the university’s buildings. Social support groups are needed where students from different educational levels, different types of disabilities and even students without disabilities can offer support to each other, share their experience concerning challenges they face at the university and ways of overcoming them. S mentioned “organizing events help students with VIs to accommodate better during their years of study” and A proceeded “and Facebook is the main platform to announce about such events and activities.”

The present study explored the QoL and the academic experiences of students with VIs at university of Jordan. The NEI VFQ-25 questionnaire was administered with students with VIs and the results showed that the composite score of the total sample was

60.12±12.8. This score falls within the stated normative range of (40-100) for life satisfaction within the general population^[23]. Albrecht and Devlieger^[24] investigated reasons for People with Disabilities (PWDs) to report high levels of life satisfaction and QoL contrary to what would be expected. The researchers explained that people with disabilities created a balance between their body, mind and spirit and formulated positive social relationships. Albrecht and Devlieger^[24] presented a justification that mirrored what students with VIs in the current investigation had mentioned concerning PWVIs’ responsibility of their lives and power to continuously adapt to challenges by accepting and using compensatory methods and using the support of their families. Thus, students with VIs feel empowered and having control over their personal lives and surrounding environments.

Table 3 presents a summary of the results of the current study and other studies that utilized the NEI VFQ-25 with PWVIs worldwide. Although, there were differences in the sample sizes across the listed studies in Table 3, the composite and the subscale scores were very close, namely in the subscales of ocular pain, distance activities, social functioning, role difficulties, dependency, peripheral vision and color vision.

However, there were recognizable differences between the general health subscale scores of this study and other studies. The general health subscale scores in this study were higher which can be attributed to differences in the mean age which was the lowest in this study compared to the other studies (Table 3). In addition, most of the participants in the current study did not have a history of other associated diseases unlike other listed studies in table.

Concerning the scores of the general vision and near activities subscales, they were the lowest in the current investigation compared to other studies (Table 3). This

can be attributed to the fact that the majority of participants in the current study were blind (n = 21).

The results of this study showed that the scores concerning the QoL in the NEI VFQ-25 do not accurately reflect the perceptions of the academic experiences as the findings from the focus groups has shown. While the scores of participants in the NEI VFQ-25 showed that they had average QoL scores, the focus group showed that students had low levels of QoL. This could be interpreted by that NEI VFQ-25 is intended to measure the QoL as related to general health, emotional and social function and daily function^[14] but not as related to academic life/experiences. The focus group showed that the QoL of participants was adversely affected by challenges related to limited resources, physical barriers and attitudinal barriers as encountered by students with VIs. These findings were consistent with the results of several research studies conducted to explore the challenges that students with VIs faced during their academic lives. For example, Joshi and Ray^[25] investigated the academic experiences of chiropractic students with VIs, they found that the lack of resources was one of the barriers to student's engagement in academic lives. The lack of disability awareness among the university's community (students and staff) was also a barrier they faced during their academic life^[25].

CONCLUSION

The QoL of students with VIs at the University of Jordan is negatively affected by lack of material and technological resources, lack of community's awareness and knowledge about VIs and proper ways of communication with PWVIs.

The NEI VFQ-25 may seem to be an insufficient tool in measuring the level of QoL among students with VIs in academic settings and the incorporation of qualitative research methodologies seems to be more informative in addressing this topic. Future research studies need to investigate the effects of factors such as gender, academic level, the school/major on the perceptions of academic experiences and QoL of students with VIs. Recommendations to promote positive academic experience and QoL are mainly centred on increasing awareness of the community about VIs and the right of PWVIs. In addition, more efforts are needed to maximize the level of support, the physical resources and the accessibility to those resources as needed by students with VIs at academic contexts. Future research studies need to investigate the effectiveness of recommendations posited by students with VIs on their perceptions of academic experiences and actual academic achievements.

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