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The Quality of Life of Students with Visual Impairments in Israel - Current Situation and Methodological Issues

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ABSTRACT. In 2007 a large scale research was done in Israel, in order to evaluate the quality of life of included students with visual impairments and blindness. The study focused on students' reports, their homeroom teachers' evaluation of their students' status, in relation to the school environment, in terms of school climate and staff attitude towards inclusion. The present paper expands on the methodological issues that underlined the investigation.

Key Words: quality of life research, visual impairments, methodological issues, humanistic orientation.

INTRODUCTION

The paper presents the theoretical and methodological issues encountered during research on the quality of life of students with visual impairments included in regular schools in Israel (Hess, 2007). The study was based on the assumption that the inclusion of students with special needs in regular schools should reflect a Humanistic-Educational Paradigm (Hess, 2007; Reiter, 2008). The most important feature of this Paradigm in relation to inclusion in regular schools is the focus on students' subjective evaluation of their quality of life (Brown, 1997; Reiter, 2008; Reiter and Schalock, 2008; Schalock, 1996; Wehmeyer, 2001).

In spite of the emphasis on listening to the students' voices, the medical model regarding people with disabilities, children and adults, still prevails in most educational settings (Reiter, 1999). The definition of 'quality of life' according to the model was based on the assessment and mapping of a large number of variables in various spheres of life. The work of Hughes and Hwang (1996) exemplifies this perception. The researchers surveyed the literature providing a summary of the definitions of the concept of quality of life. They provide a list of all the aspects of quality of life presented in 87 studies with a total number of 9,000 respondents. The respondents were of different ages and had diverse disabilities. Hughes and Hwang conducted a Meta – Analysis of the above studies based on triangulation between various quantitative and qualitative methods. The findings of the analysis provided various measures of an individual's quality of life. Fifteen measures were suggested, for example: social relations, psychological welfare and satisfaction, occupation, a sense of autonomy and free choice, utilization of leisure time, independent functioning at home and social integration.

However, the definition employed by the present researchers to assess quality of life of included students was based on the Humanistic-Educational Paradigm.

The Humanistic model of 'quality of life'

One attempt to define the components of a Humanistic Educational definition of quality of life was made by Reiter (1999, 2008). Her point of departure is a holistic perception of the person; every individual is perceived as unique and not merely a sum total of all his components. Thus the concept 'quality of life' relates to the compatibility between the individual and his environment as perceived by him, according to his own set of priorities and values. The latter are developed from childhood based on a growing self-awareness, the forging of personal identity, the sense of personal limits and of the distinctness between the self and others.

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This Humanistic Educational definition of quality of life is the same for "healthy people" as well as for those with any kind of disability.

On the above premise, several conclusions with empirical significance can be drawn for the assessment of quality of life. First, the measurement and assessment of the concept should focus on the individual's own judgment of his quality of life. A second assumption in the assessment of quality of life is that there should be congruence between the person's aspirations and the opportunities provided by the environment for their fulfillment according to individual's priorities and values. Based on these assumptions two sets of measures were applied in the research: Psychological and environmental and the interactions between the two. A further insight of the subjective experience of quality of life was obtained by in depth interviews.

The choice of subjective measures for the assessment of the quality of life of included visually impaired students – psychological measures

The subjective measures chosen to encompass the various spheres of life of visually impaired youth within the framework of inclusion were chosen on the basis of psychological and social theories.

The psychological literature proposes two main approaches to the understanding of the personal adjustment of the individual with a disability. The basis for the distinction between the approaches is the psychological paradigm according to which they have developed. One approach, stemming from the social cognitive orientation (Lazarus, 1966). This approach perceives the state of being with a disability as specific case of stress; accordingly when assessing to what extent coping with the disability is successful, one can use criteria similar to those relevant in the assessment of coping with any type of stress. The second approach, based on the assumptions of the 'dynamic school' (Parkes, 1972) explains the acceptance of the disability as similar to the experience of a loss (mourning). Therefore the assumption is that coping with the disability should be assessed by means of emotional variables. Researchers from these two schools disagree about the direction in the process and stages of adjustment of the disability. For instance, Tuttle (1987) adopts the conclusions drawn by Parkes (1972) and Bowlby (1980), namely that the stages of adjustment to the disability start with the change in emotional components (mainly depression and anxiety), and a change in the cognitive components comes at a later stage. On the other hand, Dodds and his associates (Dodds at al, 1991), while accepting the existence of stages, maintains that the process occurs in the opposite direction, namely that adjustment to being visually impaired begins with cognitive components; for instance, understanding the problem, relating to the ensuing limitations, and self-evaluation. When these components have been dealt with, a change ensues in the emotional components, such as depression and anxiety (ibid). However, even if researchers disagree as to the direction of the process, most of them share the conclusion that a more complete comprehension of the world of youth with disabilities calls for a clarification of both the emotional and the cognitive measures. Therefore these measures should be included when assessing the degree of adjustment to the disability and the attitude to it, cognitive self-evaluation and emotional states such as depression.

The statistical procedure that was adopted to test the structure validity of the psychological measures was demonstrated by correlation matrix.

The following research tools were applied in the current research:

- 1. Questionnaire on feelings of depression (CES-D) (Radloff, 1977).
- 2. Questionnaire on attitudes to disability (Nottinghaman Adjustment Scale) (Dodds at al, 1991; translated in to Hebrew by Hess, 2007).
- 3. A Self-Esteem scale (Rosenberg, 1985).
- 4. The Joyce Epstein scale of feelings towards school (Zak & Horowitz, 1985)

The statistical procedure that was adopted to test the structure validity of the psychological measures was demonstrated by a correlation matrix as presented in Table 1.

Table 1: Correlational Analyses between the psychological components (N=63)

Factor	1	2	3	4	5
1. Feelings towards school	1	-	-	-	-
2. Feeling of depression	0.28*	1	-	-	-
3 . Attitude to disability	0.31*	0.52**	1	-	-
4 .Acceptance of disability	0.192*	0.56**	0.7**	1	-
5. Self- evaluation	0.28**	0.54**	0.35**	0.45**	1

^{*}p<0.05

Table 2: Distribution of the respondents according to their assignment to the characteristics of the framework in terms of school climate and teachers' attitudes to inclusion (n=63).

Climate/attitudes	Negative	Positive	
Negative	N=17	N=16	
Positive	N=16	N=14	

Table 3: The research model

School climate/ Attitudes to inclusion	Negative climate	Positive climate
Negative attitudes to inclusion	 Negative correlations or absence of correlations between SPM and MT Negative SPM Low MT SS negative/positive high 	 Negative correlations or absence of correlations between SPM and MT SPM positive/negative Low MT SS negative/positive high
Positive attitudes to inclusion	 Negative correlations or absence of correlations between SPM and MT Negative SPM Low/high MT SS negative/positive high 	 Positive correlations between SPM and MT Positive SPM High MT No SS

^{*} SPM = Subjective Psychological Measures

Table 1 demonstrates that the measures proposed by the various psychological theories regarding adjustment to the disability are significantly correlated. This fact strengthens the structure validity of combining both emotional and cognitive aspects when assessing quality of life.

In order to complete the assessment of quality of life of included visually impaired students, it was decided to examine the level of compatibility between the teachers' assessments of their students and the students' perceptions of their quality of life.

^{**}p<0.01

^{**}MT = Measures assessed by Teachers

^{***}SS = Sense of Stigma

In the current study we chose the homeroom teachers, to be the ones to assess the students' adjustment in the emotional, social and academic spheres.

Examination of the correlation between the included students' own assessment and their teachers' evaluations of students' achievements and social status

Homeroom teachers' assessments were compared and correlated with students' self-evaluations. The assumption was that the more cognizant the system is of student's needs, and the better it identifies their unique qualities without being influenced by prejudices - the higher the level of their quality of life. This was supported by the findings of the study by Huurra, Komulainen & Aro (1999), with students with various degrees of visual impairments who were included in regular schools. The study revealed significant relationships between measures of social support and respect for each individual student notwithstanding their disabilities. Huurre at al (ibid) reported that a study replicated two year later, led to the same conclusions. Similar findings were also derived from studies in non-western countries. For instance, research carried out in Japan by Kakizawa, Douglas, Kagawa & Mason (2000) found that in schools, where the interaction with included students was sensitive to their needs, there was higher level of well being than found in places where staff were less aware of the psychological world of the students.

The sociological measure of quality of life: the felt stigma by students with visual impairments

A holistic view of the concept of 'quality of life' must include not only psychological measures of well being but also sociological considerations.

The social model of disability defines the social status of persons with disability as that of a minority group (Albert, 2006; Ainscow, 2000; Dyson, 2008). The most salient characteristic of the relations between a minority and wider society is stigmatization, as clarified by the stigma theory (Goffman, 1963; Scambler & Hopkins, 1986; Wright, 1983). According to this theory, the behavior and emotional reactions of people with disabilities can be explained against the backdrop of their constant desire to escape social stigmatization. Indeed, people with disabilities often express the wish not to be defined by their disability. This desire and efforts to be accepted into the society of the "healthy" is termed 'passing' (Wright, 1983). This phenomenon is due mainly to the existence of society's negative attitudes, compelling people with disabilities to confront rejection. Research show that the tendency to view people with disabilities in a stereotypical way is stable throughout history (Barker et al, 1953; Deshen, 1992; Safilioos Rothchild, 1970). Additional studies reveal that this rejection by society is even harder for the people with disabilities to bear than the physical disability per se (Scambler & Hopkins, 1986; Wright, 1983).

Assessment of the effects of stigmatization was thus considered to contribute to a deeper understanding of the quality of life of the included student. In the current study, we focused on the perception of stigmatization as experienced by the students themselves. This approach differs from other studies that looked at stigmatization by studying the attitudes exhibited by others such as teachers and peers. It is our contention that the subjective sense of stigma does not reflect only the direct attitudes of the close social milieu of the student, but also the general negative cultural images of the blind person. Thus, in order to get a valid picture of students' quality of life it was important to get first hand knowledge from them regarding their felt stigma. The questionnaire used for this purpose was the perceived feelings of stigmatization scale (Sade, 1981).

Environmental characteristics enabling or preventing quality of life: School climate and staff attitudes towards inclusion.

As mentioned above, a holistic view of the student emphasizes the important role played by the environment in its influence on various measures of the included students' quality of life.

Indeed, the characteristics of the including school in terms of 'school climate', have a decisive influence on the coping of students with visual impairments with school challenges (Chalifoux & Fagan, 1997; Vaughn, Elbaum, Schumm & Hughes, 1988). In the current study we were interested to find out how differences in school climate could have an effect on the quality of life of the students (Fritz & Miller, 1995).

In a previous study done by Mamalin (1999), the variables of school climate that were found to correlate with successful inclusion were: staff shared in the decision making process, management procedures, the staff's perception of the principal as democratic versus authoritative. The Inclusion was more successful in democratic schools. In Israel, Schanin (1990) found too that the decisive factors contributing to the success of inclusion were the following: cooperation among the staff, the teachers' autonomy and professional prestige. Blackman's (1989) as well as Ainscow (2000) and Wood (1998) revealed a further relationship between accessible school structure, cooperation among the staff and the success of the included students.

For this reason it was decided to use an index of school climate in the present research.

A number of authors (Halpin & Croft, 1962; Hoy, Kottkamp & Tarter, 1991; Zak & Horowitz, 1985) suggest that a comprehensive index for the school climate should include the following variables: The characteristics of the principal's supportive leadership; autonomy; shared decision-making; cooperation and prestige at work. When the measures for school mentioned above are high, we may conclude that the climate in school is positive; when they are low, it is negative.

Thus an examination of the type of school climate within the context of inclusion of students with disabilities is an important factor when looking at the quality of life of students with disabilities in general and students with visual impairments in particular.

Another variable that was found to be significant in the successful inclusion in terms of quality of life of students with disabilities is staff attitudes towards inclusion (Benstein, 1996; Gemel-Crosb & Hanzlik, 1994; Leyser & Tappendorf, 2000). Teachers' unfavorable attitude to inclusion may harm components of the students' quality of life, whatever their achievements in academic studies (Hobben, 1980). Fox and Yesseldyke (1997) examined inclusive schools and discovered that when teachers' expressed negative attitudes it created a feeling that inclusion had failed, while positive attitudes were accompanied by a sense of success. In studies dealing with people with visual impairments, a rapport was found between positive attitudes and emotional adjustment (Diebold & von Eschenbach, 1991; Houck & Rogers, 1994). Thus the school staff's attitude towards inclusion can be considered as a complementary measure, characterizing the inclusive school.

METHOD

Based on the above, a model for comprehensive empirical research, examining the relationship between measures of the students' quality of life and characteristics of the including framework was defined.

Research population

Population: The population in the current research consisted of students who are visual impairments, included in regular schools in Israel, ages 12 - 19 years old from grades 7^{th} to 12^{th} .

Sampling framework: The sampling framework was based on a "numeric list of students with visual impairments, sorted out according to junior high and high schools in Israel" (Ministry of Education, 2002). This list consisted of 223 included students in 196 schools; most of them (70%) had one student with visual impairments. In the other schools (30%), there was more than one student who is visual impairments. The average of integrated visual impairments students per school was 1.13.

Students' Sample: Israel is divided into three major education areas, South, Center and North. In order to get a representative sample from all over the country, the research sample was randomly selected from the list mentioned above, proportionally. The final sample consisted of 63 students in 40 schools all over Israel (1/4 of the Sampling framework).

In addition, for each included student the following teachers were asked to fill in questionnaires: The regular homeroom teacher, the school counselor and two other subject matter teachers. None of the teachers had a teaching certificate in visual impairments or Blindness. Since the spread of students who are visual impairments was uneven, in some cases one teacher was asked to fill in questionnaires for more than one student. The total number of teachers was 200. It should be noted that any regular

teacher is expected to accommodate students who have special needs including students who are visual impairments, even if the teacher does not have a special preparation in Special Education.

Procedure

Following approval for the research program by the Ministry of Education research committee, personal meetings were held with each of the subjects. Each student answered a questionnaire individually and was told to approach the counselor/psychologist/homeroom teacher for assistance in case of any inconvenience. In cases of difficulties in reading the questionnaires and/or answering them, the questions were read out to the student by the researcher.

Homeroom teachers and any other staff member who was professionally in touch with the research subjects filled in the questionnaires on school climate and on attitudes toward inclusion. The research instruments used here were:

- 1. Questionnaire on school climate (Halpin & Croft, 1963) translated into Hebrew by Zack and Horowitz (1985).
- 2. Questionnaire on attitudes towards inclusion (Hess, 2007). Data was collected over a period of one academic year.

At this stage the integrated database made it possible to identify for each of the 63 students not only his report on the measures of their quality of life, but also the overall index provided by the teachers for the factors: 'school climate' and 'attitudes towards inclusion'. This, together with the fact that the values of the variables 'climate' and 'attitudes' had already been merged into two levels, negative and positive, made it possible to assign each student to one of the four frameworks created, as described in Table 2.

Insert about here table 2

The examination of the independence between the variable 'school climate' and the variable 'attitudes to inclusion' showed that there is no dependence between the factors ($\chi^2 = 0.021$, df = 1, p = 0.885). This data, together with the fact that the number of respondents was divided among the 4 characteristics of the system almost equally, enabled the design of the research model: Independent variables:

- 1. Index of the school climate converted into two values 'negative' and 'positive'.
- 2. Index of attitudes to inclusion, converted into two values 'negative attitudes' and 'positive attitudes'.
- 3. Background variables: age, degree of vision, socioeconomic status.

Dependent variables:

Students' evaluation of quality of life:

- 1. Assessments based on questionnaires administered to students (attitude to school, emotional state, coping with the disability and attitude to it, self-evaluation and sense of stigma),
- 2. Assessments based on questionnaires administered to teachers (in the social, emotional and study domains).
- 3. Application of Spearman's correlations between the students and teachers measures. Table 3 demonstrates the research model.

Insert about here table 3

An ANOVA procedure was applied to the background variables in order to find out whether any of the background variables affected the Quality of Life measures. No significant differences were found. This fact strengthened the internal validity of the research model, similarly to the work by Maes and Grietens (2004). The explanation for the lack of differences may lie in the random sampling applied in this research. Random sampling assists in reducing the variance of distortions within each group (Shavelson & Towne, 2002).

Research Hypotheses

The main research hypothesis was that the measures of quality of life, as reported by the students and the teachers, would be related to the characteristics of the school climate and the teachers' attitudes to inclusion.

When both school climate and staff attitudes are positive there will be:

- 1. Positive correlations between the homeroom teachers' assessments of the students (in the social, emotional and learning domains) and the students' assessments of their quality of life (attitude to school, emotional state, coping with the disability and attitude to it, self-evaluation and felted stigma).
- 2. The measures of quality of life reported by students and homeroom teachers will be higher and the felt stigma lower.

The research also included qualitative study based on open interviews. The aim of the qualitative part was to attempt to extend our understanding of topics related to the students' quality of life; moreover, an analysis of the interviews might throw light on some of the findings derived quantitatively.

The qualitative part of the study

For the purpose of the qualitative study, 19 open ended interviews were carried out. This methodology enables the respondents to come up with answers, ideas and subjective explanations for phenomena in the course of their lives that they consider important (Crabtree & Miller, 1999; McAdams,1995; Paton, 1990).

While the open interviews were central to this study, some of them were subject to two constraints, sometimes affecting the topics brought up:

- a) The sensitive nature of the topics of the study and the interviewees' young age: The students were told that the study focused on the story of their life and the way they cope with the disability. Sometimes the interviewer (and also the students) diverted the interview to the topic of visual impairment per se; sometimes, owing to the sensitivity demanded of the researchers, the interviewer had to find indirect ways of probing the subject, less common in open interviews (Crabtree & Miller, 1999).
- b) The interviewer had to commit himself to limit the length of time of each interview. Although sometimes this led to a second meeting with the student, occasionally it also made it necessary to ask direct questions on specific topics.

In the course of the interview, the students were asked to relate to the following topics: Their personal, family and environmental background in the context of visual impairment and the attitude to it; Their life at school and the attitude of the teachers and the other students to their disability; Their feelings and experiences related to their life with visual impairment.

The students interviewed were chosen to represent each of the four groups derived from the previous quantitative part of the research

Reliability and validity of the findings of the qualitative part of the study

According to Marshall and Rossman (1995), the analysis of open interviews should include the identification of categories and recurring patterns, classified on the basis of their themes. These themes should then be analyzed according to the theoretical literature. Finally, the various themes should be integrated into a comprehensive framework. In this study, the analysis of the interviews was carried out in a similar way:

- 1. On the first level of analysis, two evaluators, not involved in the previous quantitative part of the study, were chosen to analyze the transcription of each interview. Then each one carried out a comparative analysis of the interviews to identify patterns recurring in the interviews, as a basis for the detection of general themes. At the next stage, a closer reading of the interviews enabled the classification of each relevant excerpt into a specific category.
- 2. At the end of the above process the researcher chose the themes that recurred in the reports. The validation of the shared themes was carried out by comparing the statements from which they had been extrapolated.

3. Since this study comprised almost 10% of the entire population of students with visual impairments it enabled us to identify several general trends thereby increasing the external validity of the research.

SUMMARY: Findings and discussion

The aim of the present paper was to describe methodological issues that underline a research on the quality of life of included students with visual impairments. Accordingly, findings are presented only in terms of the methodological and assumptions underline the present research. For a more detailed description of the findings see Hess (2007).

The results of this study demonstrated that in frameworks, characterized by a democratic and positive school climate and positive attitudes to inclusion- the correlations between teachers and students evaluations of the latter quality of life, were significantly higher than in other frameworks. It should be noted that if the findings had proved only that correlation, then it may be said that the school imposes its evaluations upon the students. However, it is our claim that the nature of the findings of the current research about the correlation between the student's self-evaluations and those of his or her homeroom teacher is that the student's perceptions are positioned in the center of the educational experience in these schools and therefore the findings indicate higher QOL. Our argument is based on another finding which demonstrated that students' felt stigma was lower. However, students in these frameworks did not exhibit significantly higher mean scores on the different measures of quality of life than students in the other frameworks (negative climate and attitudes, negative climate and positive attitudes, positive climate and negative aptitudes) and so did the mean scores of the teachers' evaluations.

The qualitative part of the study brought up the complexities of students quality of life. Students gave contradictory statements. For example, when talking about school they could say that their teachers did and didn't listen to them or encourage them. This finding was true of all frameworks including the one where school climate and attitudes were both positive.

On the whole, students expressed the feeling that teachers didn't listen to them in a sincere way. This was manifested in practice through their not ensuring that test and/or work pages were photocopied in an enlarged form, that more time was allotted to them and that the technical aids facilitating reading were implemented. This even in cases where the equipment was in school. These findings appeared also in schools where the students considered the teachers' attitude to inclusion to be positive. The fact that the interviewees in all the frameworks, whatever their characteristics, described a similar situation of insufficient assistance in practice, can explain the blurring of the differences in the averages, derived from the analyses of variance between the measures of quality of life.

CONCLUSION

In conclusion we may say that this study exemplified the operational definition of quality of life, based on a humanistic paradigm. This, in spite of the abstract and subjective nature of this concept. The study attempted to show that the criteria underlying the research process - such as systematic procedures, examination of the reliability and validity of the research instruments, transparency of the various procedures - is not only possible when the guiding paradigm is the humanistic orientation, but it even verifies and validates it by both quantitative and qualitative measures. Obviously, as in any scientific endeavor, there is a need for reflection and further empirical research with other populations.

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