

Quality of Life in Handicapped Children

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Background: The need for assessing the state of living or quality of life has increased in the last few decades. The quality of living rather than longevity is the significant consideration. Handicap in children represents a serious problem because it will affect their school performance and later on their productivity in the community. Assessment of health related quality of life in handicapped children allows the description from a new point of view, giving valuable information for improving their health care and for resource allocation. A case control study aims to describe the quality of life in 82 handicapped children was carried out. Cases were 57 child with hearing impairment from the school of deaf and speech difficulties and 25 child with impairment in motor function representing all cases attended the outpatient clinics of the Suez Canal University Hospital during 3 months period; from May 1 to July 31. They were compared with similar number of healthy controls from a regular public primary school. The measure used was an Arabic version of culturally modified Quality of Life Questionnaire for children used in previous studies. The questionnaire items was completed during a structured interview. A qualified teacher in the school of deaf explained questions and received children's responses with sign language and with the help of associated illustrated pictures. The results of this study point to the social and psychological problems faced by the handicapped children, whatever the nature of the impairment. However, children with impairment in motor function showed significant lower quality of life than those with hearing impairment which appears more in their reduced enjoying with hobbies and increased psychological problems which reflects the great impact of the child's view of his image on his quality of life in this age group. In contrast children with hearing impairment reported greater impact of their state on cognitive function reflecting their problem of communication. **Conclusions:** handicapped children were lesser satisfied with their quality of life than normal children, they reported social and psychological problems. This vulnerable group needs more assessment for their real problems and more attention for their need for care to help making them live with maximum capacity of function.

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INTRODUCTION

All of us are considered not only

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about the length of our lives but also about having meaningful lives. The quality of living rather than longevity is the significant consideration. For all of us a certain level of physical and material welling, safety and health is necessary as the basis for a satisfying life, on which we build the meaningful relationships, the social interaction and the personal participation that provide

the epitome of quality of life. The handicapped person has a greater problem in achieving the satisfactory quality of life (Kottke, 1982). The handicap situation results from incompatibility in the triple confrontation of an individual, a life scheme and an environment. It means maladaptation of an individual to his context or his environment (Andre, 1994)

Handicap is the social consequence of impairment or disability; it has been defined as " a disability of body or mind, which interferes with the ability to lead a normal life or to benefit from a normal education (Campbell, et al 1994). Disability is a major problem for children in developing countries . Many children have some form of impairment difficulties in moving, seeing hearing or learning (El-Defrawi, M.H. 1999). UNICEF reported that the total number of handicapped children in Egypt was 1.846 million in 1992 and expected to increase up to 2.137 million in 1997; 2.08% of them with problems in hearing and speech represented 0.5 % of them . Up to 5 per cent of children are born with a disability or become disabled during their childhood (Eunson, 1999) . As more children have the opportunity to attend school, the less obvious impairments that involve seeing, hearing and learning become more important (WHO, 1999). There are more than 120 million people in the world today with disabling hearing impairment . This can retard an individual's development by causing delay in language acquisition which impedes school progress. It can cause vocational and economic difficulties and lead to social isolation and stigmatization (WHO, 1999) . The loss of hearing modifies in every respect the relations between a child and his

environment and results in serious communication problems. Feinstein (1983) have stressed how problems in communication exert a profound effect on the lives of these youngsters, both by virtue of their past and present influence on family life, by their ongoing effect on peer - group processes and academic adjustment. Schilling and Dejesus (1993) presented an overview of the development of deaf children. The central difficulty for these children is acquiring language.

Assessment of health related quality of life (HRQOL) allows the description of different populations from a new point of view , giving valuable information for improvement of health care and for resource allocation (Walker and Rosser 1993). There is a consensus that quality of life is a multidimensional measure; it reflects the child or family's view about the impact of disability; it is not directly related to disability state or traditional clinical measures of severity (Eiser, 1997). A measure includes the basic domains of quality of life that have been identified : functional status, disease and treatment related physical symptoms, psychological and social functioning, assessing a wide range of behaviors and activities. It may not be possible to develop a brief measure for a concept, which is as broadly defined as quality of life (Apajasblo et al, 1996). Poor quality of life constitutes a real burden on the individual, family and society with national implications (Walker and Rosser, 1993) .

Children with chronic conditions and their families can experience difficulties that require professional intervention . It is established that much more needs to be known about the development of children with a major sensory deficit . In the current economic climate there is an expectation that advocate of any

intervention need to provide hard evidence that the approach works and justifies expenditure. Quality of life measures have the potential to fulfill this role.

AIM OF THE WORK

The purpose of the present study was to investigate the HRQOL & possible factors, which mediate it among handicapped children with impairment in motor function and hearing and speech abilities from the children view.

SUBJECTS AND METHODS

This study was carried out as a case control study.

Participants: All the children with normal intelligence, aged between 8 - 11 years old, attending the hearing impairment school in Ismailia City and all the children with impaired motor function attending the outpatient pediatric clinics of university hospital in the period from May 1 July 31, 1998. Controls were chosen from children graduated in an ordinary primary school in the same city. One normal child was matched for each child with hearing / language impairment as much as possible for age, sex and socio economic status.

Procedure: The instrument used was a questionnaire based heavily on the previous work of Apajasalo, et al who worked with children with similar age group. Further the dimensions included and formulation of the questions and alternatives were age appropriate, however, the continuous physical, emotional, cognitive and social development during childhood and adolescence makes the development of

a universal measure for children of all ages impossible. We were interested to study children aged 8 - 11 years because this group is homogeneous in cognitive abilities and roles chum, 1991 a factor crucial to item selection and phrasing. To maintain subjectivity, the children themselves should provide the quality of life data. The tool was cultured and modified to be applicable for handicapped children and took into consideration the cultural peculiarities of the local Egyptian Ismailia community .

The questionnaire consists of three sets of multiple choice questions, each question represented one health-related dimension. The first set included physical profile dimensions (mobility, vision, hearing, speech, sleeping, eating and vitality). The second set included social profile dimensions (elimination, hobbies and friends) and the last set included psychological profile dimensions (feeling of depression, anxiety and physical appearance, and performance : ability to concentrate learning ability and memory and somatization symptoms). The questionnaire is illustrated with pictures, a graduated tip for rating. A pilot study has been carried out on 10 with hearing impairment children for testing the questionnaire followed by some modification in phrasing and illustrated pictures. (See Appendix)

The study sample comprised three groups of children aged 8 - 11 years (1) all children aged 8 - 11 years attending the school of deaf in Ismailia City . (2) Group of children with impaired motor function (3) A control group of children from 2 elementary schools matched with the handicapped groups in age and sex. The child completed the measure during a structured interview the same interviewer carried out all the interviews. A teacher in the school of

deaf shared in the interview to facilitate communication with sign language.

Each child completed the questionnaire with the help of the interviewer. The child marks the level (1-5) of each dimension best describing his or her present health status on a special graduated ruler. Best level = 100 and worst level = 0

The individual values given to a level were averaged to obtain the desirability value of that dimension. The paired t-test was used to analyze the results. To obtain the dimension importance weights, the parents of the control group children were instructed to indicate the relative position of each dimension on an adjacent importance scale (0-100). They gave a score to the dimension according to its importance to the children in this age group from their point of view. The sum of the mean importance relative weights obtained were adjusted to equal 1 (Table 5). The overall score of the questionnaire ranging from 0 (worst possible) to 1 (best possible) is calculated by combining the dimension importance weights and within - dimension level disability value.

RESULTS

This study included 57 children with hearing impairment, 25 children with congenital and acquired limb deficiencies with impairment in motor function and 82 controls. As shown in table 1, cases and controls were rather similar in socio-demographic characteristics. All of the studied children had only single handicap. Thirteen out of 57 (22.8%) children with hearing impairment were using hearing aids. About half of the children with impairment in motor function used a

mobile chair, the same percentage had old paralytic polio. Concerning HRQOL profiles, for all handicapped and controls, table 2 shows the physical profile dimensions, a significant difference was detected between cases and controls in dimensions of mobility, hearing, speech and sleeping. However, in fig, the children with impaired motor function showed significant difference from controls with in the mobility dimension and for children with hearing impairment the difference was significant for hearing and speech dimensions. Table 3 summarizes the different social profile dimensions for all cases and controls; it shows a significant difference for the variables of hobbies and elimination and had more problems than healthy ones in practicing their hobbies. (figure 1). Table 4 summarizes the psychological profile dimensions, which showed that handicapped children had significant more problems as reported the variables: feeling of depression, anxiety and with their physical appearance. Also they had significantly more problems in learning and ability to concentrate. Somatic symptoms without definite organic cause showed no difference in between the studied groups. Children with impaired motor function showed more problems with the feeling of anxiety ability to concentrate, and physical appearance however children with hearing impairment had significant more problems in feeling of depression (Figure 1).

Figure (2) illustrates that psychological problems had the lower scores for quality of life followed by social problems, physical profile had the best scores. For children with hearing impairment the same figure illustrates that physical and social scores of the HRQOL profiles had nearly the same

Table 1
Distribution of Handicapped Children Versus Controls According Socio Demographic Characteristics

Character		Handicapped GP (n=82) no. (%)	Control GP (n=82) No. (%)
Age (years)	8-	36 (43.9)	33 (40.2)
	10-12	46 (56.1)	49 (59.8)
Sex	Male	49(59.8)	49 (59.8)
	Female	33 (40.2)	33 (40.2)
Residence	Urban	34 (41.5)	29 (35.4)
	Rural	48(58.5)	53 (64.6)
Father education	No	32 (39.0)	28 (34.1)
	Read & write	23 (28.0)	19 (23.2)
	Primary	21 (25.6)	26 (31.7)
	Secondary & high	6 (7.3)	9 (11.0)
Mother education	No	54 (65.9)	46 (59.1)
	Read & write	16 (19.5)	17 (20.7)
	Primary	12 (14.6)	19 (23.2)
Father occupation	Employer	26 (31.7)	23 (28.0)
	Laborer	34 (41.5)	21 (25.6)
	Others	22 (26.8)	38 (46.3)
Mother occupation	At work	9 (11.0)	17 (20.7)
	No	73 (89.0)	65 (79.3)

Table 2
The Mean Score ($\pm$ SD) of the Functional Profile Dimensions in Relation to the Studied Groups.

Dimension	Handicapped GP (n=82)		Control GP (n=82)		T value
	Mean	S D	Mean	S D	
Mobility	69.0	$\pm$ 18.0	69.0	$\pm$ 14.2	11.03***
Vision	97.6	$\pm$ 13.9	97.8	$\pm$ 13.5	0.09
Hearing	53.6	$\pm$ 31.3	99.1	$\pm$ 4.6	3.49***
Speech	37.3	$\pm$ 22.4	99.1	$\pm$ 4.6	24.5***
Sleeping	83.9	$\pm$ 14.3	91.7	$\pm$ 15.9	2.88**
Eating	95.9	$\pm$ 3.3	97.4	$\pm$ 13.9	1.58
Vitality	91.0	$\pm$ 21.1	87.3	$\pm$ 18.9	1.18
***P <0.001					

Table 3
The Mean Score ($\pm$ SD) of the Social Profile Dimensions in Relation to the Studied Groups.

Dimension	Handicapped GP (n=82)		Control GP (n=82)		T value
	Mean	S D	Mean	S D	
Friends	90.4	$\pm$ 17.5	94.3	$\pm$ 17.0	1.4
Hobbies	63.9	$\pm$ 18.9	90.4	$\pm$ 23.9	7.88***
Elimination	66.8	$\pm$ 18.9	92.9	$\pm$ 12.3	12.5***
** P< 0.01 ***P<0.001					

Table 4
The Mean Score ($\pm$ SD) of the psychological Profile Dimensions
in Relation to the Studied Groups.

Dimension	Handicapped GP (n=82)		Control GP (n=82)		T value
	Mean	S D	Mean	S D	
Feeling:					
Depression	51.9	± 22.2	90.4	± 16.8	6.075***
Anxiety	70.8	± 18.0	90.4	± 20.9	6.44***
Physical appearance	27.8	± 8.0	99.1	± 4.6	19.25***
Performance:					
Learning & memory	54.1	± 30.5	66.2	± 28.9	2.85**
Ability to concentrate	48.6	± 21.9	75.0	± 22.6	7.6***
Somatization	78.8	± 24.2	82.9	± 21.7	1.14

P<0.01 *P<0.001

Table 5
Importance Weighted Means of the Dimensions of HRQOL Profiles
According to the Evaluation of the Parents of Control Group.

	Weighted mean (Total =1)	SD
Mobility	0.108	0.022
Vision	0.108	0.020
Hearing	0.081	0.023
Eating	0.073	0.017
Elimination	0.072	0.019
Sleeping	0.071	0.021
Friends	0.070	0.017
Vitalit	0.068	0.024
Speech	0.065	0.019
Learning	0.054	0.017
Hobbies	0.053	0.021
Anxiety	0.042	0.027
Ability to concentrate	0.041	0.017
Depression	0.040	0.016
Physical appearance	0.028	0.013
Somatic symptoms	0.026	0.012
The sum of the total importance weights equals 1		

Fig 1
Dimensions of HRQOL of handicapped and controls

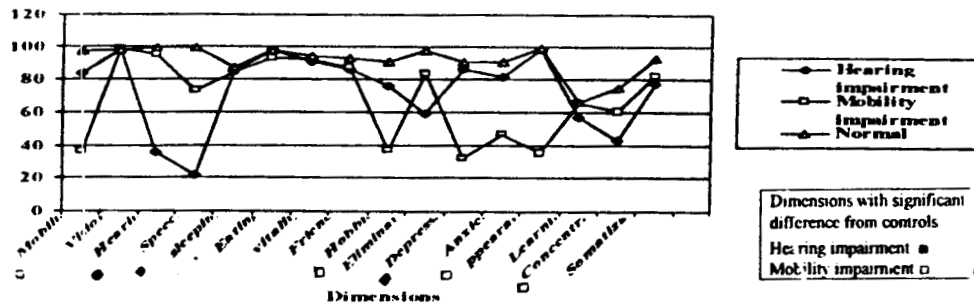
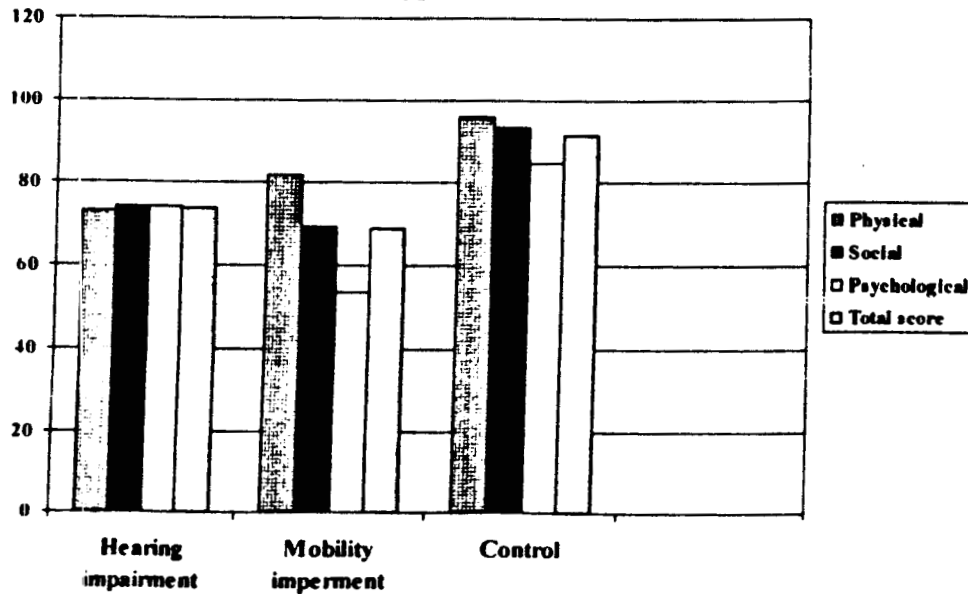


Fig. 2
Physical, social, psychological and total HRQOL scores for handicapped and controls



scores and psychological profiles scores were significantly better than the scores of children with impairment in motor function. The total weighted HRQOL score of the handicapped was significantly lower (Mean: 0.706 ± 0.065) than that of the controls. The total weighted mean scores of the children with impaired motor function and impaired hearing children were 0.736-0.054 and 0.698-0.063 respectively.

DISCUSSION

How do handicapped children evaluate their life situation? What factors are critical to achieving a good quality of life? Improving quality of life has always been a goal of health services. Lack of knowledge about subjective quality of life factors can negatively influence expectations and selection of treatment. It is apparent that children differ from adults in their views of quality of life. For this reason a debate how far adults can rate a child's quality of life. So a measure tool suitable to be rated by children was used in this study. With continuous development during childhood and adolescence, the development of one measure for children of all ages is impossible. Children in age group 8 - 11 is considered a homogeneous group in cognitive abilities and roles (Piaget, 1969). This age group especially among handicapped needs more attention and care. This study supports the use of HRQOL questionnaire filled by children. The children enjoyed filling in the illustrated questionnaire and they found most of the questions easy to understand. The total scores of HRQOL profiles of the handicapped groups were significantly lower than that of the control group. However, the group with

impairment in motor function showed lower score HROL than the group with hearing impairment. Children's parents gave the mobility profile highest rating regarding its importance to this age group which could explain its impact on children with impairment in motor function. Concerning functional profile, as expected the handicapped child significantly experienced more problems with his specific impairment, either for mobility or for hearing and speech than controls. The disabled patient has a greater problem in achieving a satisfactory quality of life. He has lost, or possibly never had, the physical capacity for the necessary responses to establish and maintain the relationships, interactions, and participation that healthy persons have.

Concerning social profile, children with impaired motor function significantly attributed their difficulties in practicing their hobbies to their problem of elimination. Schum (1991) reported high-frequency behavioral and social problems manifested by deaf children. Problems of social interaction are attributed to the delayed language development of some deaf children. However, deaf children of deaf parents are less likely to experience problems in this area and other areas of development than are deaf children of normal hearing parents. This latter group represents 90% of the population of deaf children. Vostanis et al (1993) reported that 82% of studied deaf children were socially dysfunctional compared with the general population. Individuals with physical disabilities are at greater risk of displaying depressive symptoms, their social integration is often limited (Turner et al, 1990, Viemero, 1991) and many preferred to live in social elimination. Varni and Setoguchi (1992) reported that 23% of the studied physical handicapped group were

reported to function in the clinically significant maladjustment range for behavior and emotional problems and 14% were reported in the social maladjustment range. There were no difference between cases and the controls in the dimension of friends, this complies well with the previous studies (Holmes et al, 1986, West phol, 1989) in early years of school these children are especially popular (the mascot syndrome); during puberty the friends, usually drop out.

Psychological profiles showed higher means of the different psychological aspects among handicapped children, this agreed with Hall (1988) who reported that behavioral disorders represented more than 35% of psychiatric disturbances among severely handicapped children. Illness or handicap imposes psychological stress on the child and family not only at the time of diagnosis but also in the long-term. Handicapped children seemed significantly less satisfied with their physical appearance than the controls. This finding is in agreement with earlier studies that demonstrate the increasing importance of physical appearance for the children with short stature at the onset of puberty (Siegel et al, 1991). Positive body image as assessed by the child on the basis of size strength attractiveness of the body is essential factor in development of self - confidence and a capacity for social adaptation. Child physical development is often delayed by chronic illness also their personality characters (Harald, 1989). Individuals with physical disabilities are at greater risk of displaying depressive symptoms.

Conclusions and Recommendations:

The results of this study point to the low of quality of life of handicapped

children compared with healthy children in the same age group and nearly the same socioeconomic status. Handicapped children considered that their health status had a negative impact on the different dimensions of HRQOL . Whatever the nature of the impairment, handicapped children face impairment physical, social and psychological problems. However, children with motor impairment showed significantly lower quality of life than those with hearing impairment which appears more in their enjoying with hobbies and more psychological problems which reflects the great impact of the child view his self image on quality of life in this age group. In contrast children with hearing impairment feel communication more the impact of their hearing problem on cognitive function reflecting their communication . The study points to the burden and impact of the psychological problems in reducing quality of life of handicapped children. The burden of handicapped children on the family and the community could mask the psychological problems away from the view of care givers and family. Much more is needed to be known about the development of children with a major motor and sensory deficit. The implications for care giver of handicapped children and their families is enormous and oversee needs assessment and care of vulnerable group. This information should be considered when planing for rehabilitation services for these groups.

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La capacite de vivre chez les enfants handicapes

Dans les quelques dernières années, le besoin d'évaluer l'état et la capacité de vivre a augmenté. Ainsi que le genre de vie a un sens efficace plus que la longévité. D'ailleurs, l'handicap des enfants représente un problème dangeureux, puisque il influence leur performance scolaire et de plus leur productivité dans la société. On l'évaluation de la capacité de vivre chez les enfants handicapés permet de les décrire et cela a travers différents points de vue et qui nous donne des informations volables pour développer les soins sanitaires et spécifier les ressources. Donc, cette étude vise à décrire la capacité de vie chez 82 enfants handicapés et cela en étudiant des cas comparables. Dans l'école des sons-muets, il ya un nombre de 57 enfants atteints d'un mal auditif, 25 autres atteints d'une affection musculaire: ils n'arrivent pas à mouvoir. Tous ces cas représentent ceux qui sont venus à la clinique externe de l'hôpital de l'université durant 3 mois. En outre, On les a comparés avec d'autres cas primaire ordinaire. On, la manière d'évaluation employée était à travers d'un fiche de questionnaires se rapportant à la capacité de vivre des enfants et qui était-elle utilisée dans des études précédentes. Par suite de cette étude, on a pu dégager les problèmes sociaux et psychologiques qu'affrontent les enfants handicapés. Quelque soit la nature du mal. Malgré cela, les enfants empêchés de mouvements représentent une capacité de vivre moins que les autres dont l'audition est affectée. Cette capacité se montre dans le fait de fournir de leurs loisirs et dans leurs problèmes psychologiques qui reflètent l'influence de la vision de l'enfant sur sa capacité de vie à cet âge. Par contre, les enfants atteints d'un mal auditif sentent l'influence de leur problèmes sur le pouvoir de comprendre et qui surtout reflète le problème de communication chez eux. Bref, les enfants handicapés acceptent leur vie par opposition aux enfants naturels aussi sentent-ils leurs problèmes sociaux et psychologiques. Ce groupe sensible a en plus, besoin qu'on évalue leur problème véritables et veule qu'on s'intéresse à leurs soins qui leur sont présentés et qui les poussent à vivre avec la plus grande capacité.

كفاءة الحياة فى الأطفال المعاقين

ازداد فى العقود القليلة الاخيرة الاحتياج لتقييم نوعيه الحياة أو كفاءة الحياة. حيث تحتل الاعتبار ذو الفاعلية أكثر من طول الحياة، وتمثل الاعاقة فى الأطفال مشكلة خطيرة حيث أنها ستتؤثر على أدائهم المدرسى وفيما بعد على قوة انتاجهم فى المجتمع.

إن قياس كفاءة الحياة فى الأطفال المعاقين تسمح بوصفهم من وجهة نظر مختلفة وتعطى معلومات قيمة لتنمية رعايتهم الصحية ولتخصيص الموارد لهم. تهدف هذه الدراسة إلى وصف كفاءة الحياة فى ٨٢ طفل معاق ومناظرتهم بدراسة حالات مقارنة.

ضمت الدراسة ٥٧ طفل مصاب بعطب فى السمع من مدرسة الصم والبكم و ٢٥ طفل مصاب بعطب فى الحركة يمثلون كل الحالات التى ترددت على العيادة الخارجية لمستشفى جامعة قناة السويس فى فترة ثلاثة أشهر (١ مايو إلى ٣١ يوليو) ١٩٩٨ وقد تمت مقارنتهم مع مجموعة مماثلة من الأطفال الاصحاء من مدرسة ابتدائية عادية، وكانت طريقة القياس المستعملة هى استمارة استبيان خاصة بكفاءة الحياة للأطفال مترجمة ومعدلة ثقافيا للعربية ومستخدمة فى دراسات سابقة وقد تمت تغطيه بنود الاستمارة فى مقابله شبه مقننه مع الأخذ فى الاعتبار وجود مدرس لشرح للأطفال الاسئلة ويتلقى لاستجابات بطريقة التخاطب بالاشارات مع الرسومات الموضحة. تشير نتائج هذه الدراسة إلى وجود المشاكل الاجتماعية والنفسية التى تواجه الأطفال المعاقين مهما كانت طبيعة العطب، ومع ذلك فقد أظهر الأطفال ذوى العطب فى الحركة كفاءة حياة اقل ذات دلالة احصائية عن الأطفال المصابين بعطب فى السمع حيث تظهر اكثر فى قلة استمتاعهم بالهوايات وكثرة المشاكل النفسية التى تعكس التأثير الكبير لنظرة الطفل لصورته على كفاءة الحياة فى تلك المرحلة العمرية والعكس فى الأطفال ذوى العطب فى السمع حيث يشعرون أكثر بتأثير مشكلتهم على قدرتهم على الفهم التى تعكس مشكلة الاتصال عندهم، الخلاصة أن الأطفال المعاقين راضون بصورة اقل بنوعية حياتهم عن الأطفال الطبيعيين ويشعرون بمشاكل اجتماعية ونفسية، وهذه الفئة الحساسة تحتاج إلى تقييم أكثر لمشاكلهم الحقيقية واهتمام اكثر بالرعاية المقدمة لهم والتى تجعلهم يعيشون باقصى كفاءة ممكنه للحياة.

Appendix : Some items of HRQOL Questionne Questimaire

١ - هل حالتك الصحية تمنعك أو تقلل من حركتك فى الذهاب لى مكان؟

١٠٠ - بتاتا

٧٥ - شوية

٥٠ - إلى حد ما

٢٥ - غالبا أيوة

٠٠ - أيوة طول الوقت

٢ - هل حالتك الصحية تمنعك من مصاحبة زملاؤك أو تقلل من عدد أصحابك؟

١٠٠ - بتاتا

٧٥ - شوية

٥٠ - إلى حد ما

٢٥ - غالبا أيوة

٠٠ - أيوة طول الوقت

٣ - هل حالتك الصحية تجعلك غير راضى أو مش مبسوط من شكلك أو مظهرك؟

١٠٠ - بتاتا

٧٥ - شوية

٥٠ - إلى حد ما

٢٥ - غالبا أيوة

٠٠ - أيوة طول الوقت

٤ - هل حالتك الصحية تجعلك غير قادر على التعليم فى المدرسة ومتابعة الدروس؟

١٠٠ - بتاتا

٧٥ - شوية

٥٠ - إلى حد ما

٢٥ - غالبا أيوة

٠٠ - أيوة طول الوقت

(هذه الأسئلة والاختيارات مصحوبة برسومات وأشكال تشير إلى المعنى المطلوب ونوعيه الصعوبه أو الاستمتاع).