

ORIGINAL ARTICLE

QUALITY OF LIFE AND ITS INFLUENCING FACTORS AMONG PHYSICALLY DISABLED TEENAGERS IN KUALA LUMPUR, MALAYSIA

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ABSTRACT

A cross-sectional study was conducted from December 2009 till May 2010 to determine the quality of life and factors influencing it among physically disabled teenagers. Data were collected from 59 physically disabled teenagers using guided questionnaire Short Form 36 (SF-36) and General Health Questionnaires 12 (GHQ 12). Quality of life among physically disabled teenagers is low for most domains of SF-36 as compared to the general Malaysian population. There was significant difference in quality of life among different races (mental health domain) and among different educational level and type of disability (physical functioning domain). There was no significant association between general health domain and other variables. Higher satisfaction in house, school and recreational environment showed a better quality of life. Higher stress level had a lower quality of life. Lack of disabled friendly environment at home, school and recreational places probably contribute to their quality of life. Schools and public places should have more disabled friendly facilities to improve independency and accessibility. Better education and training will increase their independence and enhance self-confidence. More attention and support at this age is important for them to develop interpersonal skills and character for their future.

Keywords: quality, life, physically disabled, teenagers

INTRODUCTION

The World Health Organization (WHO) defines Quality of Life (QoL) as individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment¹. Teenagers are experiencing the period of developmental transition between childhood and adulthood. It involves changes in many aspects including personality, physical, intellectual and social development. During this time of change, teens face with many issues and decision². This is when an individual builds their thoughts and dreams. Hence, an improvement and change done during this stage in life creates the most impact in an individual's quality of life (QoL).

Each member of the society deserves a good QoL despite their physical well-being or social status. However, not every member of the public is able to appreciate good level of quality of life especially physically disabled people^{3, 4}. Among physically disabled teenagers, limitation in performing chore or action encountered has an impact on their

QoL. Disabled teenagers desire similar attention and care as non-disabled. They want to be part of the local community, acquire social and self-care skills for future independence, feel confident and respected by others. However, what these outcomes meant, the way they are prioritised, and the level of achievement expected, often differed from normal teenagers⁵.

There are weaknesses in system of identification and detection, negative attitudes, and exclusionary policies and practices towards disabled. Most development of buildings, facilities, roads and footpaths, as well as public transport systems are being built without considering the needs of the physically disadvantaged group⁶. Inadequate training of students with a wide range of abilities, lack of support systems for teachers, lack of appropriate teaching materials and devices, and failure to make modifications to the school environment to make it fully accessible was another back draws in the system towards disabled teenagers⁷. Some teenagers with special needs did not experience even basic and routine activities⁸.

Physically disabled teenagers are also thought to have impaired psychological status and well-being. Patients with spinal cord injuries have an increased risk of suffering debilitating levels of

psychopathology⁹. Studies also showed that compare with the normal teenagers^{10, 11}. There are many factors which could determine and influence QoL of physically disabled teenagers. Some of the factors which are focused in this research are the socioeconomic status, educational status, facilities at home and rehabilitation centre, type of disability, psychological status and well-being. The aim of this study is to evaluate the QoL of the physically disabled teenagers and to determine factors associated with it.

METHODOLOGY

This cross-sectional study was carried out from December 2009 till May 2010. Fifty-nine physically disabled teenagers were accepted as respondent for the survey. They were from orthopaedics outpatient clinic, rehabilitation medicine department, physiotherapy department (Universiti Kebangsaan Malaysia Medical Centre - UKMMC and Hospital Kuala Lumpur - HKL) and from secondary schools around Kuala Lumpur based on list provided by the Ministry of Education of Malaysia. The inclusion criteria were: (i) physical disability such as polio, amputee, muscular dystrophy, myopathy, neuropathy, osteogenesis imperfecta, spinal cord injury and others with duration of the disablement which is more than 6 months, (ii) teenagers (age from 13-19 years old), (iii) Malaysian citizen, (iv) agree to participate in the study, and (v) stay in Kuala Lumpur. The exclusion criteria were (i) blind, deaf and dumb teenagers, (ii) have learning disability, (iii) temporarily disabled, (iv) mentally disabled, and (v) teenagers who cannot respond to the questionnaire.

Guided questionnaires were used in the data collection, including: (i) demographic data, (ii) clinical data of disability as well as environmental accessibility such as type of disability, duration of disability, type of mobility aids, self-satisfaction of respondent toward home, school, and recreation environment, (iii) QoL using Short Form 36 (SF-36)¹², (iv) general health and stress level using General Health Questionnaire 12 (GHQ 12)¹³.

QoL was measured using the generic Short Form 36 (SF-36) version 1, administered as part of a self-administered questionnaire. Questions in the SF-36 are related to general health and to physical and emotional health

they usually have a lower self-esteem over the past four weeks. Responses from the 36 items were coded into eight dimensions, namely physical functioning (PF), role-physical (RP), bodily pain (BP), general health (GH), vitality (VT), social functioning (SF), role-emotional (RE), and mental health (MH), and the two derived summary scales, the physical component summary (PCS) and the mental component summary (MCS). The eight dimensions were transformed to a scale of 0-100 and the two summary scales were aggregated from z-score transformations of the eight dimensions and then transformed to a median and a inter quartile range (IQR) 25%-75%. Three domains were given priority in the analysis of our study which are physical functioning, general health and mental health. These 3 domains are widely discussed in various literatures.

The 12-item General Health Questionnaire (GHQ-12) is one of the most widely used tools to measure stress levels¹⁴. Various studies have demonstrated that the reliability of GHQ-12 coefficients ranges from 0.78 to 0.95^{13, 15}. The items on the GHQ-12 represent 12 manifestations of stress, and respondents were asked to rate the presence of each of these manifestations in themselves during the recent week preceding the study period¹³. Subjects respond to each question by choosing from four typical responses: 'not at all', 'not more than usual', 'rather more than usual' and 'much more than usual'. A binary scoring method is used to evaluate responses. This method assigns a score of zero to the two least symptomatic answers and a score of one to the two most symptomatic answers; thus, responses can only be scored as zero or one.

Data were analysed using Statistical Package for Social Sciences (SPSS) version 19.0¹⁶. The significance level was set at 0.05 and confidence interval of 95%. Descriptive statistics were used for the analysis of the demographic data, and teenager's clinical status. Statistical analysis conducted include Spearman Correlation, Mann-Whitney U, and Kruskal-Wallis one way ANOVA test. This study was approved by the Ethical Committee of Universiti Kebangsaan Malaysia Medical Centre (UKMMC).

RESULT

The demographic characteristics are summarized in Table 1. Out of 59 respondents, 37(62.7%) were male. Malay is the majority, 31(52.5%) compared to Chinese (39.0%) and Indian (8.5%). Mostly, 41(69.5%) went to secondary school and above while 18(30.5%) went to primary school. Majority of their parents were doing non-professional jobs (86.4%) with median household income of MYR 1800.00 (IQR: 1000.00, 2750.00). The most common type of disability is due to non-spinal cause, 30 (50.8%). Median duration of disabilities is 168 months (IQR: 69,183). Most respondents (67.8%) used mobility aids and 51(86.4%) respondents received social support. Among them, 31(60.7%) received financial support, 11(21.5%) received mobility aids and 9(17.6%) received health support. Most of our respondents do not have full time helper at home (maid), 45 (76.3%) with easy accessibility to hospital and rehabilitation centre, 50 (84.7%) and actively involved in organization/ society, 32 (54.2%). In general , the mean quality of life among physically disabled teenagers is low for most domains of SF-36 compared to the general Malaysian population as shown in Table 2¹⁷.

Table 1: Socio-demographic characteristics of respondents

| Characteristics | Frequency | (%) |
|---|-----------|--------|
| Gender | | |
| Male | 37 | (62.7) |
| Female | 22 | (37.3) |
| Race | | |
| Malay | 31 | (52.5) |
| Chinese | 23 | (39.0) |
| Indian | 5 | (8.5) |
| Educational level | | |
| Primary school and below | 18 | (30.5) |
| Secondary school and above | 41 | (69.5) |
| Type of Jobs for Parents | | |
| Non-professional | 51 | (86.4) |
| Professional | 8 | (13.6) |
| Type of Disability | | |
| Spinal cause | 29 | (49.2) |
| Non-spinal cause | 30 | (50.8) |
| Mobility Aids | | |
| Use mobility aid | 40 | (67.8) |
| Do not use mobility aid | 19 | (32.2) |
| Social Support | | |
| Receive social support | 51 | (86.4) |
| Financial | 31 | (60.7) |
| Mobility aid | 11 | (21.5) |
| Health support | 9 | (17.6) |
| Without social support | 8 | (13.6) |
| Full Time Helper at Home (Maid) | | |
| Yes | 14 | (23.7) |
| No | 45 | (76.3) |
| Accessibility to Hospital and Rehabilitation Centres | | |
| Yes | 50 | (84.7) |
| No | 9 | (15.3) |
| Active in Organization/ Society | | |
| Yes | 32 | (54.2) |
| No | 27 | (45.8) |

Table 2: Comparison of mean quality of life for all domains in SF-36 between disabled teenagers and the general Malaysian population

| Domains in SF-36 | Disabled Teenagers Mean (\pm S.D) | General Malaysian Population ¹⁷ Mean (\pm S.D) |
|----------------------|--------------------------------------|--|
| Physical functioning | 41.9 (\pm 29.1) | 85.9 (\pm 17.9) |
| Mental Health | 55.6 (\pm 13.9) | 74.6 (\pm 35.9) |
| General Health | 48.9 (\pm 11.8) | 66.7 (\pm 19.9) |
| Role-Emotional | 59.9 (\pm 41.9) | 79.2 (\pm 17.2) |
| Role-Physical | 37.3 (\pm 32.9) | 82.0 (\pm 32.1) |
| Bodily Pain | 79.9 (\pm 20.3) | 69.9 (\pm 17.6) |
| Vitality | 51.7 (\pm 11.7) | 66.8 (\pm 17.7) |
| Social Functioning | 42.2 (\pm 15.9) | 83.7 (\pm 19.3) |

There is no significant difference in quality of life between sexes. Table 3 shows there is significant difference between races ($p=0.02$) in mental health domain whereby Malay has the highest score with median of 72.0 (IQR: 60.0, 84.0) compare to Chinese

and Indian. However, there is no significant difference in quality of life at different age. The professional group parents have higher quality of life in role-emotional domain, with median of 100.0 (IQR: 75.0-100.0) compared to non-professional parents with median of 66.7 (IQR: 0.0-100.0) with $p = 0.045$. On the other hand, there is no significant correlation between household income and quality of life.

Respondents with education level of secondary school and above have higher quality of life in role-physical domain, with median of 50.0(IQR:25.0-75.0) compared to education level of primary school and below with median of 0.0(IQR:0.0-50.0). The difference is significant at $p=0.006$. Nonetheless, in physical functioning domain, respondents with education level of secondary school and above has higher quality of life with median of 40.0(IQR: 30.0,70.0) compared to education level of primary school and below with median of 20.0(IQR: 3.8,40.0). The difference is significant at $p=0.01$.

Table 3: Association between sociodemographic factors and 3 main QoL domains

| | Mental health Median (IQR) | Physical Functioning Median (IQR) | General Health Median (IQR) |
|---|---------------------------------------|--|--|
| Sex | | | |
| Male | 72.0 (60.0,84.0) | 35.0 (15.0,57.5) | 57.0 (52.0,82.0) |
| Female | 62.0 (56.0,77.0) | 50.0 (20.0,71.3) | 57.0 (39.3,72.0) |
| <i>p</i> value ^a | 0.30 | 0.35 | 0.23 |
| Race | | | |
| Malay | 72.0 (60.0,84.0) | 35.0 (20.0,70.0) | 60.0 (52.0,82.0) |
| Chinese | 60.0 (56.0,72.0) | 40.0 (16.7,70.0) | 52.0 (47.0,77.0) |
| Indian | 60.0 (46.0,66.0) | 40.0 (20.0,57.2) | 52.0 (49.5,62.0) |
| <i>p</i> value ^b | 0.02* | 0.73 | 0.25 |
| Educational level | | | |
| Primary school and below | 74.0 (53.0,81.0) | 20.0 (3.8,40.0) | 57.0 (51.5,72.0) |
| Secondary school and above | 64.0 (60.0,76.0) | 40.0 (30.0,70.0) | 57.0 (50.0,79.5) |
| <i>p</i> value ^a | 0.64 | 0.01* | 0.97 |
| Types of disability | | | |
| Spinal Cause | 64.0 (56.0,82.0) | 25.0 (10.0,40.0) | 57.0 (51.0,72.0) |
| Non Spinal Cause | 72.0 (60.0,80.0) | 52.5 (33.8,76.5) | 57.0 (47.5,82.0) |
| <i>p</i> value ^a | 0.48 | 0.01* | 0.62 |
| Mobility aids | | | |
| Yes | 70.0 (60.0,83.0) | 35.0 (15.4,63.8) | 57.0 (50.0,72.0) |
| No | 64.0 (56.0,72.0) | 50.0 (30.0,85.0) | 57.0 (52.0,82.0) |
| <i>p</i> value ^a | 0.34 | 0.11 | 0.83 |
| Social Support | | | |
| Yes | 72.0 (56.0,80.0) | 35.0 (16.7,70.0) | 57.0 (52.0,77.0) |
| No | 62.0 (60.0,75.0) | 60.0 (23.8,70.0) | 53.5 (38.0,65.3) |
| <i>p</i> value ^a | 0.68 | 0.36 | 0.19 |
| With Full Time Helper at Home (Maid) | | | |
| Yes | 62.0 (56.0,81.0) | 32.5 (3.8,67.5) | 52.0 (50.0,73.3) |
| No | 72.0 (60.0,80.0) | 35.0 (20.0,70.0) | 57.0 (50.0,79.5) |
| <i>p</i> value ^a | 0.48 | 0.30 | 0.54 |
| Access to Facilities | | | |
| Yes | 70.0 (60.0,80.0) | 40.0 (20.0,70.0) | 57.0 (51.5,78.3) |
| No | 60.0 (56.0,86.0) | 25.0 (10.0,55.0) | 52.0 (46.0,72.0) |
| <i>p</i> value ^a | 1.00 | 0.25 | 0.33 |
| Participation in organization | | | |
| Yes | 70.0 (60.0,79.0) | 35.0 (16.3,63.8) | 57.0 (50.0,75.8) |
| No | 68.0 (56.0,84.0) | 35.0 (20.0,70.0) | 57.0 (47.0,77.0) |
| <i>p</i> value ^a | 0.97 | 0.68 | 0.91 |

a: Mann-Whitney U b: Kruskal-Wallis Test

IQR: inter-Quartile Range

** p < 0.05*

Likewise, in physical functioning, type of disability due to non-spinal cause has higher score with median 52.5 (IQR: 33.8, 76.5) compared to disability due to spinal cause. The difference is significant with

$p=0.01$. Even so, there is no significant difference in quality of life among physically

disabled teenagers with and without mobility aids.

Teenagers with full time helper at home (maid) have higher score in role-emotional domain with median of 100.0 (IQR: 66.7 - 100.0) compared to teenagers without maid. This difference is significant with $p=0.017$. On the other hand, there is no significant

correlation between duration of disability of physically disabled teenagers and their quality of life. Moreover, there is no significant difference for quality of life between teenagers with social support and teenagers without social support. Similarly, no significant difference was noted among physically disabled teenagers who are involved in any organizations or those that are not involved in any organization. There is no association between quality of life and accessibility to facilities such as rehabilitation centre and hospital.

Table 4 shows a significant positive correlation for satisfaction of house environment and domains role-emotional,

role-physical, vitality, physical functioning and mental health ($p < 0.05$).

However, other domains showed no significant correlation. There is a significant positive correlation for satisfactions of school environment and quality of life in domains of role-emotional and general health. There is a significant positive correlation for satisfactions of recreational environment and quality of life in domains role-emotional, vitality and physical functioning. There is a significant correlation of stress level based on GHQ12 and quality of life in domains role-emotional, role-physical, vitality, general health, social functioning and mental health.

Table 4: Correlation analysis between the quality of life domains and level of satisfaction on the environments and stress

| Domains | House Environment | | School Environment | | Recreational Environment | | GHQ12 | |
|----------------------|-------------------|-----------|--------------------|-----------|--------------------------|-----------|-------|-----------|
| | r_s | p value | r_s | p value | r_s | p value | r_s | p value |
| Role-Emotional | 0.35 | 0.01* | 0.36 | 0.01* | 0.46 | 0.01* | -0.45 | <0.001* |
| Role-Physical | 0.35 | 0.01* | 0.18 | 0.22 | 0.27 | 0.11 | -0.31 | 0.02* |
| Bodily Pain | 0.16 | 0.23 | -0.02 | 0.90 | 0.03 | 0.85 | -0.12 | 0.39 |
| Vitality | 0.34 | 0.01* | 0.22 | 0.13 | 0.41 | 0.01* | -0.52 | <0.001* |
| General Health | 0.18 | 0.17 | 0.45 | <0.001* | 0.21 | 0.21 | -0.32 | 0.01* |
| Social Functioning | 0.09 | 0.48 | 0.18 | 0.23 | 0.13 | 0.45 | -0.32 | 0.02* |
| Physical Functioning | 0.46 | <0.001* | 0.19 | 0.20 | 0.33 | 0.04* | -0.22 | 0.09 |
| Mental Health | 0.27 | 0.04* | 0.27 | 0.07 | 0.28 | 0.09 | -0.33 | 0.01* |

* $p < 0.05$

DISCUSSION

This study showed several significant factors pertaining to the quality of life among disabled teenagers. Both sexes are entitled for same facilities and environment. Malay respondents have higher score for mental health domain. To certain extent, cultural background might influence their lifestyle due to differences in beliefs, environment and social interaction. Besides that, there is no difference in quality of life at different ages because the range of age among the respondents is too narrowed. Being in the same age group, they generally face the same type of problem as they are going through the same phase of life at this point in life.

Parents with professional occupation have higher score in role-emotion domain. This is most probably due to higher awareness among the parents regarding their children’s condition. Exposure to low parental educational status may reduce quality of life in childhood, while reduced access to material resources could lead to a lower quality of life mainly in teenagers¹⁸. Besides, better education can be provided by the parents to the children and thus emotional support.

In general, respondents with higher household income are expected to have better access to more resources and support. However, there was no association found between household income and quality of life among disabled teenagers. Household income is not an absolute factor

that determines quality of life among the teens. Income effect on children outcome is small. Family income in the United States led to an increase of merely 3% of a standard deviation of children's outcome¹⁹.

Respondent with educational level of secondary school and above shows higher quality of life in physical role and physical function compared to primary school and below. Based on a study conducted on factors affecting quality of life in patients with coronary heart disease, it is proven that the patients graduated from high school or university have higher quality of life scores than those graduated from primary schools²⁰. Emotional and physical distress like depression, anxiety, anger, pain and malaise were lower in well educated people. This is most probably due to their ability to be more independent in their activities of daily living due to having better skills in handling themselves. Besides, they have better understanding of their condition which enables them to function better physically. Since they are better educated, they tend to take more effort to carry out their own activities without burdening others²¹.

In this study, disability due to spinal causes consists of tetraplegia, paraplegia, cerebral palsy and spinal related disabilities while disability due to non-spinal cause consists of amputees and others. Result shows that respondent with disability of non-spinal cause have higher physical function compared to disabilities due to spinal cause. Physical function consists of walking 100 yards, bathing, dressing, bending, kneeling, climbing a flight, lifting and carrying groceries and other moderate activities. Amputee patients are usually more mobile, able to do chores and self-managed with the help of prosthetic limb. Moreover, according to a research carried out on a group of adults with Spinal Cord Injuries (SCI), they were found to have raised levels of psychopathology, 20% of the respondents had increased level of negative psychological states which synonymous with psychiatric disorder. The researchers concluded that people with SCI have an increased risk of suffering debilitating levels of psychopathology⁹. This supports our finding that the type of disability carries some impact on the quality of life.

There was no difference in quality of life in physically disabled teenagers with or without mobility aids. Even though they have mobility aids, the environment might not be conducive for them to move around comfortably with their mobility aids. The duration of disability is also not the factor affecting the quality of life. Despite increasing duration, lack of improvement in therapy and conducive environmental support, there would not be significant change in quality of life. In spite of the availability of social support, quality of life does not show any difference between those who received and those who did not. The services provided might not be sufficient enough in or fulfilling the needs of the disabled. Although having a proper structure, the organization did not manage to explore the needs of the physically disabled teenagers. They might not feel the sense of security.

Involvement in organizations does not show any difference in their quality of life. Even though they are registered with an organization, they might not participate in activities which are organized. Children and adolescents with disabilities seldom participate in organized sport or physical activities even if there are good integrated sport programmes^{22, 23}. Furthermore, their physical limitation restricts them from taking an active participation. Often the sport experiences of children with disabilities are limited due to lack of requisite skills, overprotection by adults, social isolation, and time required for their treatment or care, or lack of available programmes and trained leaders^{24, 25}.

Having a fulltime helper at home (maid) makes them emotionally more stable and thus they are able to carry-out their activities of daily living more effectively. They receive extra care and always have a person to attend to him/her at all times. Accessibility to facilities such as to rehabilitation centre and hospital does not influence the quality of life among them in all domains. This research was carried out in urban area where public transport is easily available for everyone and those who stay in homes for disabled have their own transport to mobilise them. Thus, the impact found to be insignificant. Housing environment which is more physically disabled friendly will

improve independency of the disabled person. Those who live in a house with a better and satisfactory environment will have a higher quality of life in terms of role-emotional, role-physical, vitality, physical and mental.

A satisfactory school environment have a better quality of life in the term of general health and role emotional domain. If the schools environments are suitable for physically disabled students, they will be able to move around independently and they do not feel indifferent compared to their peers. This gives self-confidence and reinforces the worthiness. Similar things apply for sport and recreational facilities which show better quality of life in role emotional and vitality domains. In general, teenagers enjoy sport and recreational activities to keep themselves occupied and to reduce their stress. Besides, participation in sports makes them feel more energetic which improves their vitality due to stability in their emotions and minds.

Higher stress level leads to lower quality of life. The way a person perceives and their coping skills will determine their stress level. Physiological and behavioural response will be initiated when we face stressful situation and lead to adaptation. However, after repeated stressful experiences, the physiological response will cause accumulation of various mediators which can damage the body. Thus, it will cause them to get sick easily. They will be less energetic, lack of motivation, poor concentration and even have poor appetite which can worsen their health and mental status. Eventually, their physical functions or activities of daily living are affected²⁶.

CONCLUSION

This study concludes that the quality of life is affected by factors mainly the ethnicity, educational level, type of disability, stress level and environmental satisfaction. Schools and public places should have more disabled friendly facilities to improve independency and accessibility. Better education and training which is tailored for their physical condition should be given to increase independency and to reinforce self-confidence to improve the quality of life. Social organisations should structure an improved network to reach out to the

disabled teenagers and keep track of all data. Non-governmental organisations should move forward to form support groups to reduce and alleviate stress among physically disabled teenagers. More attention and support should be given to the physically disabled teenagers as this is the age when they start to develop interpersonal skills and their character as a whole which will reflect in their future.

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