Iranian J Publ Health, Vol. 37, No.3, 2008, pp.29-35

Original Article

Measuring Perceived Quality of Life to Assess Health Needs among People with MS: A Community Study in Derbyshire, UK

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(Received 28 Jan 2008; accepted 12 Jul 2008)

Abstract

Background: To determine the health needs of people with multiple sclerosis living in the Southern Derbyshire region of the UK, using a quality of life postal questionnaire.

Methods: This was a population-based survey using a postal questionnaire comprising the 54-item Multiple Sclerosis Quality of life questionnaire (MSQOL-54), Nottingham Extended Activities of Daily Living (ADL), and some additional demographic questions. A postal questionnaire was sent via 40 health practices (50% of general practitioners) in Southern Derbyshire to all patients diagnosed with Multiple Sclerosis confirmed by a neurologist.

Results: Two hundred and one completed questionnaires (from 223 respondents) were returned using pre-paid postage. Respondents were divided into those with mild (41%), moderate (36%) and severe (23%) disability on the basis of their ADL scores. Seventy seven percent (155) of respondents were women. The POQL mean scores for three groups of mild, moderate and severe disability were 12.0±2.8, 9.5±3.0, and 8.0±3.5 (out of 17), respectively. The regression model showed a relationship between disability scores and POQL scores (Beta=0.58, *P*= 0.000).

Conclusion: For the three groups of disabled people, different priorities emerged in relation to POQL, indicating that services seeking to improve quality of life in these groups must identify and target the relevant issues appropriately and be sensitive to the differing requirements reported by individuals at different levels of disability. Studies of this type are becoming increasingly important for determining which outcomes should be measured when evaluating interventions designed to maintain well-being and protect the health of patients with MS.

Keywords: *Quality of life, Health needs, Multiple sclerosis, MSQOL-54*

Introduction

Epidemiologists have defined "health needs" as "the ability of people to benefit from health care” (1). For the purpose of assessing health needs it is important to establish a number of health parameters. These parameters must reflect the real needs of people who use health care services. As one of these parameters, there has been a growing interest in recent years in defining and measuring quality of life (QOL) (2-3).

In UK, Recent developments in the management of Multiple Sclerosis (MS) also recognise the importance of the “Expert Patient” and emphasise self-management in the care of people with MS(4). Quality of life issues are also central to this approach. It is difficult to assess the experience of living with MS, in particular it is not known precisely how individual health determinants impact on quality of life nor which domains have the greatest influence.

There is generally a prolonged period of life between the average age of MS onset and mortality among patients (5). The wide range of symptoms and unpredictable nature of the course of the disease are special characteristics (6). Recent reforms in UK health policy have emphasised the importance of independently assessing the health needs of local populations (7). The ultimate aim of this kind of assessment of health needs is to maximise the total amount of benefit derived from health care services, within existing resources.

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The purpose of this postal survey was to present data derived from the 54-item Multiple Sclerosis Quality of Life (MSQOL-54) questionnaire in order to address several objectives: to determine those needy areas of respondents lives that are more important for improving the quality of life, to investigate the relationship between some variables including descriptive variables (age, gender, living with others, marital status, occupational status, perceived dependency, duration of disease, co-morbidity, and having a main carer), nine MS specific symptoms, access to equipment, and using of services with the perceived overall QOL; and to assess the effect of severity of disease on need among people with Multiple Sclerosis (MS) resident in Derbyshire.

Materials and Methods

The work was approved by Southern Derbyshire Ethical Committee and informed consent was taken from both general practices and patients. All MS patients registered in half of health practices in Southern Derbyshire were invited to help with this postal survey. This proportion represents a cluster random sample. People were included in the study if they were diagnosed by a neurologist as having MS. In the UK, health care provided by the National Health Service (NHS) is available to everyone. It can be assumed that each person (healthy or ill) in the UK population is registered with a family doctor working in a health practice. Therefore all MS patients had an equal chance of being invited via their local health practice to take part. Forty (out of 80) health practices were randomly selected from the latest version of the list of health practices throughout Southern Derbyshire. The consent of health practices was obtained prior to starting data collection. A letter was sent to these health practices seeking help in identifying patients with a diagnosis of MS. The health practices sent back the number of their MS patients only if they were willing to participate. Then, adequate numbers of packages were sent to health practices being sent out to MS patients. The patients who were willing to participate received, via their GPs, the questionnaire along with a consent form, an invitation letter, and pre-paid envelope to send back the filled questionnaire.

MSQOL-54(8) which is based on the 36-item short form (SF-36) (9) was selected as the core of the study questionnaire. Some items, descriptive variables (10 items), MS specific symptoms (nine items), access to equipment (five items), and use of services (10 items) were added to form the study instrument. Nottingham Extended Activities Daily Living (ADL) was also used for assessing the severity of respondents' disability (10).

Health practices were randomly selected using a random number table. Administrative databases were developed to monitor the data collection process. Fields were added to the databases to accommodate all stages of the data collection process some of which had been suggested by Ethical Committees. Tracking down letters and questionnaires in health practices was conducted by telephone. Invitation letters, along with the protocol of the study, were sent to selected health practices (50%). After three weeks one telephone call was made to each health practice asking whether they had received the letter and if they were willing to help the researchers to contact MS patients. A second invitation letter was sent to them if they had not received the first.

Health practices who agreed to take part sent questionnaires in pre-paid envelopes to all MS patients registered with them. The identity of the patients was never disclosed to the research team. The researcher asked health practice managers to write the name and address of each eligible patient on the outgoing health practices' pre-paid envelope and to seal and post it. The address of the researcher was typed on pre-paid envelopes so that respondents could return their completed questionnaires directly to the research team.

Respondents were asked to provide a telephone number to reduce the number of missing items of data. Where a number was provided, one telephone call was made only if any critical items were missing from the returned questionnaires. Finally a letter was sent to those health practices willing to take part in the research seeking information to compare the age and gender of MS patients who participated in the survey with those who did not. As before no individual patients were identified.

Data analysis

The statistical package SPSS was used for data analysis. In the results which follow, descriptive variables (demographic variables, social situation, and disease related variables) of respondents are presented using descriptive statistics.

In the questionnaire, data were collected, using existing scales, on activities of daily living and quality of life. The quality of life instrument used had been developed specifically for use with people with MS (8). The 14 domains of quality of life were measured by the MSQOL-54. One general domain named "overall quality of life" measured perceived overall quality of life (POQL). POQL was measured using a summation of scores from two items- a visual analogue scale (scored between 0 to10) and a closed question (scored from 1 (terrible) to 7 (delighted)). The lowest score for respondents was 1 (worst situation) and the highest score was 17 (best situation). The remaining 13 individual domains of these were examined as predictors of perceived overall quality of life (POQL); "physical health", "role limitation due to physical problems" (RLPP), "emotional wellbeing", "role limitation due to emotional problems" (RLEP), "social functioning", "energy", "health distress", "pain", "health perception", "cognitive function", "change in health", "sexual functioning", and "satisfaction with sexual function".

Since POQL scores were normally distributed, the researcher used parametric tests to determine the difference between groups based on this variable. Multiple regression models were used to measure the effects of different QOL domains in forming POQL. However, the distribution of data derived from the remaining domains of the QOL questionnaire were not normal, so non-parametric statistical tests were therefore used. Hierarchical Multiple Regression method enabled the researchers to control the effect of age and the severity of disability on the models.

Results

Response rate

Pilot study attending 15 MS patients showed that the instrument items including MSQOL-54 are acceptable and understandable among MS patients. The average of answered questions was 97%.

Seventy seven percent of health practices agreed to help with the survey and reported a total number of 370 registered MS patients (a mean of 11.9±8.1 patients for each health practice). Of the 370 patients contacted, 223 respondents (60%) returned questionnaires and of these 201 (54%) were completed. No significant difference was found between the age and gender of participants and non-participants.

Descriptive variables

The 201 respondents could be divided into those with mild (41%), moderate (36%) and severe (23%) disability on the basis of their ADL scores. Seventy seven present (155) of respondents were women. There was no significant difference between the mean ages of men (53±11.6 yr) and women (50.5±12.9 yr). The majorities were living with others (86.5%) rather than living alone (13.5%), 30% were employed, and 54% (106) perceived themselves to be dependent on others. Three quarters (75%) were married. A minority reported co-morbidity (5%). Respondents reported disease duration of less than 6 yr (14%) 6-20 yr (53%) and more than 20 yr (32%). 62% had a main carer.

Disease specific symptoms

Overall 22.0% were not comfortable in a chair and 18% reported their unsteady weight. 35% had some problems with their vision, 20% reported leakage from bowels, and 17.0% had difficulty swallowing. Thirty seven present reported falling in the last 4 wk and 58% had urinary problems. Painful muscle spasms and problems with speaking were reported by 54% and 21% of respondents respectively. Proportions of respondents in the three groups of disability reporting different MS symptoms are presented in Table 1.

Access to equipment and use of services

Fifty five percent, 24%, and 42% had access to equipment for moving around, in the kitchen, and in the bathroom, respectively. Access to equipment on the stairs and elsewhere in the home was reported by 26% and 31%, respectively. Forty three percent had never seen a consultant in the last 12 months; a district nurse had visited only 35.5% and 23.5% had had a consultation with an occupational therapist. Surprisingly, in view of the high proportion reporting speech problems only 6% were visited by a speech therapist. Thirty nine percent, 18%, 17% had consulted a physiotherapist, a social worker and a care assistant respectively. Only a minority had visited a day centre in the last 12 months (6%) and 20% had received home help.

Perceived Overall QOL (POQL)

The POQL mean scores (out of 17) for three groups of mild, moderate and severe disability were 12.0±2.8, 9.5±3.0, and 8.0±3.5, respectively. The regression model shows a relationship between disability scores and POQL scores (Beta= 0.58, *P*= 0.000). There was no difference between the POQL scores of different age and gender groups. Overall, employed respondents (*t*= 6.4, *P*= 0.000) and those who perceived themselves to be independent (*t*= 6.1, *P*= 0.000) reported significantly better scores of POQL. Those who had a main carer reported significantly worse scores of POQL (t= 5.0, *P*= 0.000).

POQL scores were associated with different MS specific symptoms in the three disabled groups. Mildly disabled respondents who had difficulty swallowing (*t*= -2.8, *P*= 0.007) and those who had at least one fall in the last 4 weeks (*t*= -2.9, *P*= 0.006) reported significantly worse scores of POQL than those who had not these problems. Among moderately disabled respondents, those who were not able to speak clearly had worse scores of POQL than those who were (*t*= 2.1, *P*= 0.037). In the severely disabled group, those with leakage from bowels (*t*= -2.3, *P*= 0.027) and those with painful muscle spasms (*t*= -2.1, *P*= 0.03) reported significantly worse scores of POQL than those without these problems.

POQL scores observed among those who had access to equipment and those who were using services were no better than those who did not have access to equipment and were not using services and this may reflect the generally poorer health status of those gaining greater access to equipment and services.

Individual domains of QOL

The 13 sub-domains of quality of life were categorised into 5 general domains in order to determine the contribution of each general domain in forming POQL. A hierarchy could then be established for each of the three levels of disability. This is shown in Table 2.

Hierarchical regression models showed that the most important domain in all three groups was the psychological domain. The second most important domain for the mild and moderate groups only was sexual functioning. In the severely disabled group, the second most important domain was physical functioning.

Table 1: The proportion of respondents in three groups of disability reporting different MS symptoms

MS Symptoms (in the last 4 weeks)	**Severity of Disability**							
	Mild		**Moderate**		**Severe**		**Total**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Not being comfortable in a chair	7	10.4	14	25.5	15	35.7	36	22.0
Not having steady weight	11	16.4	12	21.4	7	17.1	30	18.3
Suffering vision problem(s)	16	23.9	22	39.3	20	47.6	58	35.2
Having leakage from bowels	8	11.9	12	21.4	12	30.0	32	19.6
Having difficulty swallowing	4	6.0	10	17.9	14	33.3	28	17.0
Experiencing fall(s)	28	26.9	30	54.5	17	40.5	65	39.6
Not being able to speak clearly	10	15.2	9	16.1	16	38.1	35	21.3
Having urinary problem(s)	30	44.8	37	66.1	28	68.3	95	57.9
Having painful muscles spasm	27	40.9	34	60.7	28	66.7	86	54.3

Table 2: The Importance of Each General Domain in Forming Perceived Overall Quality of Life.

	Severity of disability			Total
	Mild	**Moderate**	**Severe**	
First	Psychological	Psychological	Psychological	Psychological
Second	Sexual	Sexual	Physical	Physical
Third	Physical	Cognitive	Sexual	Sexual
Fourth	Social	Social	Cognitive	Social
Fifth	Cognitive	Physical	Social	Cognitive

Discussion

The results confirmed that it is potentially possible to enhance the POQL among MS patients regardless of their age and gender. This study has also helped to identify which domains of POQL play the most important role in forming POQL among respondents.

Those mildly disabled respondents who were employed showed better POQL scores than those who were not. This means that for this group of MS patients there might be a circular relationship between working and POQL scores. Although, our results did not show the effect of age and gender on POQL, Jorngarden et al. concluded that among apparently healthy adults, males reported better health related quality of life than females and also younger respondents reported better health related quality of life than older groups (11). The discrepancy between the results of our study and this study should be considered when comparing quality of life between people suffering from some levels of disability and healthy groups.

No relationship was observed between the duration of symptoms and POQL scores in any of the three disability groups. This could be because of the ability of respondents to compensate for their individual symptoms by adapting to their situation over time. Interestingly, among respondents with the same level of disability, better scores were not observed among those who had a main carer compared with those who had not. One explanation might be that if those respondents who had a carer had not had one, their POQL scores might be significantly worse. One of the other factors which can be important affecting health related quality of life is co-morbidity. Although in our study only a minority of 5% reported co-morbidity, it has been shown that it is significantly associated with a reduced health related quality of life (12) and should be considered when measuring QOL among MS patients.

Each of the three disabled groups drew attention to different MS specific symptoms in relation to their POQL scores. This suggests that interventions aimed at each group must focus on the most important problems present at that level of disability. For instance, fall was reported among considerable proportions of all respondents regardless the severity of their disability. Interventions as same as what is suggested by Vaapio et al. for people in community-dwelling aged (13) could be helpful for the target population of our study.

The proportions of patients who had access to equipment and had been used services showed that more efforts are needed to utilise them. This looks even more important when comparing between the proportion of patients with a special problem and the proportion of patients who were using related services. For example 21% of respondents reported problem with speaking clearly, whereas only 6% of respondents had use speech therapist service.

The absence of better POQL scores at all levels of disability among respondents who had access to equipment and services, than those who had not, does not necessarily indicate that these were not helpful. Although only relatively small numbers of respondents in all categories of disability made use of current services, there was greater use of them by respondents with higher levels of disability. A comparison of POQL scores of respondents made before and after gaining access to newly available equipment and services (whilst controlling for confounder variables) would permit a more satisfactory assessment of services and equipment.

For all three groups of disability, the most important domain in forming POQL was the psychological domain and this confirms the results of Rothwell et al. (14). This study, therefore, emphasises the importance of working on this domain to improve MS patients' lives. Although the physical domain is the second most important general domain of severely disabled respondents' lives, the sexual domain of mildly and moderately disabled respondents is the next priority for enhancing POQL of these MS patients. These results confirm the results of previous studies that emphasised the importance of the sexual domain of MS patients lives (15-16).

This is an important community-based study and one of the first of its kind in the UK to examine quality of life from the patient's perspective. Studies of this type are becoming increasingly important for determining which outcomes should be measured when evaluating interventions designed to maintain well-being and protect the health of patients with chronic diseases such as MS.

For the three groups of disabled people, different priorities emerged in relation to POQL, indicating that services seeking to improve quality of life in these groups must identify and target the relevant issues appropriately and be sensitive to the differing requirements reported by individuals at different levels of disability.

The results of this study also showed that more evaluations targeted on enhancing utilisation of equipment and current services are also needed. This might include two different areas of working on these facilities for improving their quality, and seeking the users views about them for increasing their interest to use them.

Acknowledgements

The authors would like to thank all Southern Derbyshire Health Practice staff who helped with this survey, Rafsanjan University of Medical Sciences for helping with a part of the funding, and all MS patients who participated in this survey. The authors declare that they have no conflict of interests.

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