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EXPLORING FACTORS AFFECTING QUALITY OF LIFE (QOL) IN PEOPLE WITH PARKINSON'S DISEASE (PWP) IN INDIA: A FOCUS GROUP DISCUSSION (FGD) WITH PROFESSIONALS

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PDQ 39;
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Abstract

Parkinson's Disease is a progressive disorder with motor and non motor symptoms specifically affecting quality of life of people with this disease. Health related quality of life scales for Parkinson's Disease developed in various countries like Parkinson's Disease questionnaire 39 and 8, Parkinson's Disease Quality of Life, Parkinson's Disease Quality of Life Scale and Parkinson's Disease Impact Scale may not include all factors affecting quality of life in Indian people with Parkinson's Disease. Professionals of Parkinson's Disease and Movement Disorder Society of India caring for them through support group services were invited for interview and focus group discussion with an aim to explore these factors and come to consensus on frequency of occurrence of these in their clients attending support group sessions. Professionals view on factors affecting quality of life in Indian people with Parkinson's Disease is reported in this study.

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1. Introduction

Parkinson’s disease (PD) prevalence varies greatly throughout world, where Asia has low prevalence of PD reported to be 646 per 100,000 population (1). Quality of Life in Parkinson’s disease is greatly affected by its motor and non motor symptoms (2–5). Enhancement of QOL in health care has now become an important factor in health care services (6).

Outcome measures which are used for measuring QOL in People with Parkinson’s disease are Parkinson’s Disease questionnaire 39 (PDQ 39), Parkinson’s Disease questionnaire 8 (PDQ 8), Parkinson’s Disease Quality of Life (PDQOL), Parkinson’s Disease Quality of Life Scale (PDQUALIF) and Parkinson’s Disease Impact Scale (PIMS) (7). There are various environmental, social, economic and cultural factors also associated with QOL in PwP and it varies in different countries. India has prevalence of PD of 14-41 per 100,000 population and it is reported that treatment of PD in India has evolved to be through support groups in various regions of India (8). Parkinson’s disease and Movement Disorder Society (PDMDS) have been working through this support group mechanism to improve care for PwP at national level. They work through team of neurophysicians, neurosurgeons, social workers, physiotherapist, experts of Yoga, dance and music therapy, speech therapist, clinical psychologists, caregivers, counselors and many more allied health professionals. These professionals get to know problems of Indian PwP with their distinct environmental, social, economic and cultural background on a day to day basis and they meet them atleast once to a maximum of 4 times in a month. Aim of this study was to tap this resource of professionals to understand factors affecting QOL in Indian PwP through a Focus Group Discussion (FGD). This methodology is now gaining importance in health care and medical research to come to consensus about any topic, assessing condition, understanding illness related behavior and also to explore attitudes towards health care services (9).

2. Research Method

Ethical clearance for this study was obtained from Institutional Ethical Review Committee (IERC) of Mahatma Gandhi Mission’s Institute of Health Sciences (MGMIHS), Navi Mumbai, Maharashtra, India. 34 professional experts working for Parkinson’s disease and Movement Disorder Society (PDMDS) all over India were mailed a semi structured questionnaire consisting of demographic details and open ended questions on dimensions affecting Quality Of Life (QOL) in PwP along with details of purpose, methodology and consent form for this study. They were asked to report on problems faced by Indian community affected with Parkinson’s Disease (PD) under four headers of Parkinson’s symptoms related complaints, general wellness /systemic symptoms, social functioning and emotional functioning specific to Indian socio-economic-cultural background. They also had scope to enumerate other problems reported by PwP.

Responses received under each dimension in descriptive form were qualitatively reviewed and expressions were formed which can affect QOL in PwP. They were listed to form discussion guide for focus group discussion (FGD). Venue of meeting was PDMDS, Mumbai which was communicated to professionals. Focus group also included a note taker to capture what was expressed in meeting. Moderator of meeting was researcher herself.

Focus group discussion began with welcome and moderator introduced herself and note taker to professionals. Researcher briefed about topic of discussion, objectives of meeting and time duration of meeting which was about 3 to 4 hours. Informed consent was signed by all professionals present in meeting. Discussion guide with list of expressions retrieved through mails and operational definitions of terminologies to be used in discussion was presented to focus group. It was specified that discussion should be based on their experiences of interaction with PwP in support groups. They were also instructed to have Indian environment, socio-economic and cultural background in their conscious while framing statements.

It was informed that final outcome of meeting will be defining factors in form of definite statements which affect QOL in PwP and also to allocate them in specific dimension based on their knowledge on already existing health related quality of scales for Parkinson’s disease (PD). They also had to rank order statements in terms of frequency of occurrence in PwP by means of a Likert scale ranging from 1 to 5 (never reported to very frequently complained/occurred in PwP). Mode of responses received was considered as measure of consensus or agreement amongst professionals.

3. Results and Analysis

20 professionals (59%) responded to mailed questionnaire initially. They were 9 Clinical Psychologist, 7 Physiotherapist, 2 Medico Social Worker, and 2 generally qualified professionals with mean age 28.17 ± 5 years. They were working in close association with PwP for 3.8 ± 2.9 years of experience and reported to care for minimum 15 to maximum 300 PwP per month depending on enrollment of PwP in their respective support groups.

13 professionals (mean age 29.2 ± 6.4 years) participated in FGD. They were 5 Clinical Psychologist, 5 Physiotherapist, 1 Medico Social Worker, 1 Ayurvedic doctor and 1 generally qualified professional working with PDMDS, Mumbai.

57 factors affecting QOL in Indian PwP were generated under 7 dimensions following intense discussions on agreement and disagreement on each expression in this focus group discussion. **Table 2** presents expressions generated, allotted dimensions, mode, frequency and percentage of responses per expression.

Table 2: Factors generated, allotted dimensions, mode, frequency and percentage of responses per expression

Sr. No	**Factors generated**	**Dimension**	**Mode**	**1**	**2**	**3**	**4**	**5**
1	Felt stiffness in any part of the body	BD	5	1(7.7)	0(0)	2 (15.4)	4(30.8)	**6 (46.2)**
2	Felt excessively sweaty irrespective of influence of weather	BD	3	1(7.7)	4 (30.8)	**6 (46.2)**	2 (15.4)	0 (0)
3	Felt tired easily	BD	4	0(0)	1(7.7)	3(23.1)	**4 (30.8)**	**4 (30.8)**
4	Unbearable pain in hands and legs	BD	3	0(0)	3 (23.1)	**5 (38.5)**	4 (30.8)	1 (7.7)
5	Inability to manage symptoms during certain time of the day	BD	4	0 (0)	0 (0)	2 (15.4)	**8 (61.5)**	3 (23.1)
6	Uncontrollable movements in any part of the body	BD	4	1(7.7)	0(0)	3 (23.1)	**7 (53.8)**	2 (15.4)
7	Drooling of saliva.	BD	3	0 (0)	2 (15.4)	**6 (46.2)**	5 (38.5)	0 (0)
8	Had difficulty in remembering things more than before	CF	4	0 (0)	1 (7.7)	4 (30.8)	**6 (46.2)**	2 (15.4)
9	Heard or seen people or objects or any living thing around me which	CF	3	0 (0)	3 (23.1)	**6 (46.2)**	3 (23.1)	1 (7.7)

	others say does not exist							
10	Difficulty in understanding things easily more than before	CF	3	0 (0)	1 (7.7)	**7 (53.8)**	4 (30.8)	1 (7.7)
11	Got distracted easily during activities.	CF	2	0 (0)	**5 (38.5)**	3 (23.1)	4 (30.8)	1 (7.7)
12	Felt confused while performing any task	CF	3	0 (0)	2 (15.4)	**7 (53.8)**	4 (30.8)	0 (0)
13	Felt obsessed with certain things or activities	CF	2	2 (15.4)	**5 (38.5)**	4 (30.8)	2 (15.4)	0 (0)
14	Felt that people are trying to harm you	CF	3	1 (7.7)	4 (30.8)	**6 (46.2)**	1 (7.7)	1 (7.7)
15	Had felt that my facial expression do not show what I feel	COM	3	1 (7.7)	1 (7.7)	**6 (46.2)**	2 (15.4)	3 (23.1)
16	Had difficulty in communicating with people	COM	5	0 (0)	0 (0)	1 (7.7)	5 (38.5)	**7 (53.8)**
17	Had difficulty to talk over the phone	COM	4^{a}	0 (0)	0 (0)	3 (23.1)	**5 (38.5)**	**5 (38.5)**
18	Felt depressed/sad	EF	4^{a}	0 (0)	1 (7.7)	2 (15.4)	**5 (38.5)**	**5 (38.5)**
19	Felt excessively worried or concerned	EF	4	0 (0)	0 (0)	4 (30.8)	**7 (53.8)**	2 (15.4)
20	Avoid sharing feelings with family & friends	EF	3	0 (0)	2 (15.4)	**6 (46.2)**	4 (30.8)	1 (7.7)
21	Felt family members/people do not understand me/or my problems	EF	5	0 (0)	2 (15.4)	3 (23.1)	3 (23.1)	**5 (38.5)**
22	Felt lonely	EF	3	0 (0)	3 (23.1)	**4 (30.8)**	3 (23.1)	3 (23.1)
23	Felt that I am a burden to family or society	EF	3	1 (7.7)	0 (0)	**5 (38.5)**	4 (30.8)	3 (23.1)
24	Had lost interest in living	EF	2^{a}	0 (0)	**4 (30.8)**	3 (23.1)	**4 (30.8)**	2 (15.4)
25	Got angry more than before	EF	3	0 (0)	1 (7.7)	**7 (53.8)**	4 (30.8)	1 (7.7)
26	Fear of future	EF	3^{a}	0 (0)	3 (23.1)	**4 (30.8)**	**4 (30.8)**	2(15.4)
27	Felt neglected	EF	3	0 (0)	3 (23.1)	**7 (53.8)**	1 (7.7)	2 (15.4)
28	Had difficulty in walking independently within home	PF	4	0 (0)	1 (7.7)	3 (23.1)	**7 (53.8)**	2 (15.4)
29	Had difficulty in moving/walking on roads/pavement independently	PF	5	0 (0)	0 (0)	2 (15.4)	3 (23.1)	**8 (61.5)**
30	Had difficulty travelling in public	PF	3^{a}	0 (0)	0 (0)	**5 (38.5)**	3 (23.1)	**5 (38.5)**

	transport							
31	Had difficulty in moving around in crowded places for e.g.: market, wedding, parks etc	PF	5	0 (0)	0 (0)	3 (23.1)	2 (15.4)	**8 (61.5)**
32	Felt activities take longer time than before	PF	5	0 (0)	0 (0)	1 (7.7)	3 (23.1)	**9 (69.2)**
33	Felt like you were losing balance during any activity	PF	4	0 (0)	0 (0)	2 (15.4)	**6 (46.2)**	5 (38.5)
34	Objects have fallen from my hands	PF	3	0 (0)	1(7.7)	**7 (53.8)**	3 (23.1)	2 (15.4)
35	Had difficulty with sleeping or excessive sleepiness during the day	PF	3[a]	0 (0)	0 (0)	**5 (38.5)**	**5 (38.5)**	3 (23.1)
36	Faced problems with urination	PF	4	0 (0)	2 (15.4)	5 (38.5)	**6 (46.2)**	0 (0)
37	Had difficulty in using toilet	PF	3[a]	0 (0)	3 (23.1)	**4 (30.8)**	**4 (30.8)**	2 (15.4)
38	Regular bowel problems/difficulties (diarrhea/ constipation)	PF	5	0 (0)	0 (0)	1 (7.7)	4 (30.8)	**8 (61.5)**
39	Felt difficulty in swallowing food or water or any liquid	PF	4	0 (0)	0 (0)	5 (38.5)	**7 (53.8)**	1 (7.7)
40	Had difficulty in writing	PF	5	0 (0)	0 (0)	3 (23.1)	2 (15.4)	**8(61.5)**
41	Had difficulty in sexual activities	PF	3	2 (15.4)	3 (23.1)	**5 (38.5)**	3 (23.1)	0 (0)
42	Felt dizzy	PF	3	0 (0)	3 (23.1)	**7 (53.8)**	3 (23.1)	0 (0)
43	Had difficulty in sitting and getting up from the floor	PF	4[a]	0 (0)	0 (0)	3 (23.1)	**5 (38.5)**	**5 (38.5)**
44	Had difficulty in turning in bed	PF	3	0 (0)	1 (7.7)	**5 (38.5)**	4 (30.8)	3 (23.1)
45	Required help in daily activities	PF	4	0 (0)	3 (23.1)	3 (23.1)	**5 (38.5)**	2 (15.4)
46	Decreased participation in pastime activities that you enjoyed before	SF	4	0 (0)	1(7.7)	5 (38.5)	**6 (46.2)**	1 (7.7)
47	Had difficulty in carrying out bank and official work	SF	5	0 (0)	0 (0)	4 (30.8)	4 (30.8)	**5 (38.5)**
48	Had difficulty in participating in your occupation	SF	4	0 (0)	0 (0)	4 (30.8)	**7 (53.8)**	2 (15.4)
49	Had quarrel with spouse /family members	SF	3	0 (0)	3 (23.1)	**5 (38.5)**	3 (23.1)	2 (15.4)
50	Felt family member/ people stop me from doing things I feel I am capable of doing	SF	3[a]	0 (0)	1 (7.7)	**4 (30.8)**	**4 (30.8)**	**4 (30.8)**
51	Avoid social gathering e.g.:	SF	5	0 (0)	1 (7.7)	3 (23.1)	4 (30.8)	**5 (38.5)**

	wedding, functions, movies etc							
52	Avoid meeting close friends and family	SF	3	0 (0)	1 (7.7)	**7 (53.8)**	3 (23.1)	3 (23.1)
53	Felt embarrassed in public due to PD	SF	5	0 (0)	2 (15.4)	2 (15.4)	4 (30.8)	3 (23.1)
54	Felt being less important in family and society	SF	2[a]	1 (7.7)	**4 (30.8)**	**4 (30.8)**	1 (7.7)	3 (23.1)
55	Felt problems faced due to PD is because of past life sins/karma	STIG	2	1 (7.7)	**5 (38.5)**	4 (30.8)	2 (15.4)	1 (7.7)
56	Felt uncomfortable when people stare at me in public because of my condition	STIG	4	0 (0)	2 (15.4)	3 (23.1)	**5 (38.5)**	3 (23.1)
57	Felt uncomfortable in disclosing about PD	STIG	3	1 (7.7)	3 (23.1)	**5 (38.5)**	2 (15.4)	2 (15.4)
[a.] Multiple modes exist. The smallest value is shown								
Figures in bold presents highest response on particular factor								
Figures in parentheses indicate percentage								
Likert Scale : 1 = Never reported by PwP ; 2 = Rarely reported by PwP ; 3 = Occasionally reported by PwP ; 4 = Often reported by PwP ; 5 = Always reported by PwP								
Dimensions : BD = Bodily Discomfort ; CF = Cognitive Functioning ; COM = Communication ; EF = Emotional Functioning ; PF = Physical Functioning ; SF = Social Functioning ; STIG = Stigma								

4. Discussion and Conclusion

This study highlights problems faced by People with Parkinson's disease (PwP) which affect their quality of life (QOL) with specific environmental, social, economic and cultural background of India.

Results of focus group discussion suggest that cardinal features of Parkinson's disease i.e. tremors, bradykinesia, rigidity and postural instability do affect QOL in PwP as reported in various studies (10,11). Non motor symptoms like fatigue, attention/memory and psychiatric problems affect QOL in a negative way in PwP as observed by professionals and also reported by Barone et al 2009. Gallagher et al 2010 reported that depression was very strongly associated with QOL in PwP. Their study also reported that fatigue, sleep problems, pain, psychiatric complications, gastrointestinal problems, thermoregulatory problems decrease health related QOL which may remain unreported. Professionals involved in this discussion reported on similar factors affecting their clients in support groups. They picked up and reported all mild to severe issues of PwP being constant source of support and people trust them to share their day to day problems, which are then solved through multidisciplinary care extended by support group system. Social functioning is an aspect where Indian socio-economic and cultural background plays an important role. Indian community due to extended family and strong family ties has strong support system in place (8,11). PwP attending support groups are mostly accompanied by spouses, daughters/sons or any close relatives. Problem in Indian society lies in male dominance. Most of PwP were males who being the man of household draw maximum attention from family members. They also tend to avoid sharing feelings with family members and feel being less important to family members after being affected with PD. Ray et al 2006 and Singhal et al 2003 reported similar observations in their study (8,12,13). Mutual understanding amongst family members is observed to get affected by professionals in this study, which may be due to chronic illness becoming a source of conflict eventually affecting family ties (14).

Physical functioning in Indian community includes many activities which are done either with cross legged sitting on floor, long sitting on floor or squatting, for e.g. prayers, eating on floor, mopping floor, child care, gardening, farming in rural areas, toileting activities using Indian style toilets etc. PF #37 (Had difficulty in using toilet) and PF #43 (Had difficulty in sitting and getting up from the floor) was intensely discussed by professionals and they concluded that these activities will be restricted due to inability to sit and get up from floor or squat which will eventually lead to poor QOL in PwP. Also, specific to Indian community travelling involves use of public transports like auto rickshaws, cycle rickshaws, local train, trams, bus, metro rails, carts etc with low accessibility. PF#30 (had difficulty in travelling) was extensively discussed by professionals.It was debated that negotiating travel was occasionally or always reported by PwP depending on their extent of use of public transport. PF#41(Had difficulty in sexual activities) was documented as a factor affecting QOL which was occasionally reported by PwP.Though,talking about sexual life is considered a social taboo in India and people are shy to speak about it(12), professionals reported that this factor did come up in their individual sessions with PwP and can have negative impact on QOL in them.

To summarize, this study brought out factors which can exclusively affect QOL in PwP in India considering typical environmental, socio-economic and cultural background. Most of quality of life scales do not include these factors and hence they might prove to be affective to judge QOL as outcome measure. Relevant tools specifically PDQ 39 has been widely used (7) and its psychometric properties have been extensively studied. Literature reports that social support dimensions of PDQ 39 may not be sufficiently reliable to be used as final outcome, was unable to generate good internal consistency and discriminate severity of PD (15–18). Tools measuring socioattitudinal environment affecting QOL in PD is scarce. There is a need to develop tool to evaluate QOL in Indian PwP incorporating all factors relevant to Indian environment, socio-economic cultural background which can be used as outcome measure instead of measures which are developed in other countries based on experiences of patients in respective countries.

Conflict of interest

The authors declare that they have no conflict of interest.

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