

**HEALTH LITERACY, SOCIAL SUPPORT AND EMPOWERMENT
AMONG PARKINSONS PATIENTS – A CROSS SECTIONAL STUDY**

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ABSTRACT

In the past two decades, there has been an increased interest in the development of self management programs for people with chronic diseases. Fundamental to chronic disease management is adequate literacy and health literacy skills. Research on the health literacy skills of individuals managing Parkinson's disease (PD) is seemingly absent from the research literature. The purpose of this study was to assess the health literacy skills of older adults managing PD and to examine the relationships of functional health literacy, self-efficacy, social support, and empowerment in this population. Using a cross sectional design,

this study surveyed 50 older adults living with PD within north Malabar region in Kerala. Functional health literacy was positively correlated with self-efficacy ($r=.12$) and empowerment ($r=.22$) in individuals living with PD. As well, there was an association between functional health literacy and social support. Findings suggest that self-efficacy, social support, and empowerment may affect PD patients' ability to find, read, understand, and communicate health-related information.

KEYWORDS: Parkinson's disease, functional health literacy, self-efficacy, empowerment, social support.

MATERIALS AND METHODS

Using a non-experimental, cross-sectional design, this study examined the relationships of functional health literacy, self-efficacy, social support, and empowerment in individuals living with PD within the north Malabar region in Kerala. A non-experimental design is fitting given the lack of research into these relationships among individuals managing PD (Polit & Beck, 2008). Ethical approval was attained for the study by AL Iqbal Hospital Trichur ethics board. Convenience sampling was conducted to recruit participants for this research. Convenience sampling is a type of non-probability sampling, which involves recruiting the most available people as study participants. For inclusion in the study, volunteer participants were required:^[1] to be 18 years of age or older,^[2] to self-report a diagnosis of PD,^[3] to have cognitive capacity to participate in the study as measured by a score of 25 or greater on the MMSE (Folstein, Folstein, & McHugh, 1975), and^[4] to be able to read, speak, and write in English. A score of 25 or greater on the MMSE indicates normal cognition (Folstein et al., 1975). Scores less than 25 can indicate cognitive impairment. The MMSE was used in this study to help assess whether participants would be able to adequately complete the study requirements (e.g., surveys). In order to determine an estimated sample size for this study, a power analysis was conducted using G-Power. A medium effect size approximates the average size of observed effects in many fields and is commonly used when no research is available to assess effect size for the population (Cohen, 1992). Based on the selected parameters, a total sample size of 50 individuals was calculated.

Data Collection

Interested participants contacted the researcher to arrange a face-to-face interview for data collection. All interviews were arranged at a time that was most convenient for participants in order to accommodate patients associated with P.D. Data collection interviews took place in hospital; Each data collection interview lasted approximately 60 minutes. At the beginning of each interview, the study purpose and processes were reviewed again with the participant and any participant questions were addressed.

Functional health literacy

Currently available health literacy assessment tools only assess prose and numeric health literacy skills. There are no formalized or psychometrically tested assessment tools that assess interactive and critical health literacy skills. Functional health literacy was measured using the S-TOFHLA (Parker et al., 1995). The S-TOFHLA measures functional health

literacy, which includes numeracy and prose comprehension. Participants who score 0 to 53 are considered to have inadequate functional health literacy, those scoring 54 to 66 have marginal functional health literacy, and participants who score 67 to 100 have adequate functional health literacy.

Self-efficacy

There are various self-efficacy measurement tools available including the GSES (Schwarzer & Jerusalem, 1995), as well as more task-oriented scales such as the Exercise Self-Efficacy Scale (Resnick & Jenkins, 2000). The GSES (Schwarzer & Jerusalem, 1995) was chosen for this investigation over a more task oriented scale because this study did not examine any one task in particular. The GSES is comprised of ten items, and each item is ranked using a four-point Likert scale (1 – not at all true, 2 – hardly true, 3 – moderately true, 4 – exactly true). A total score ranging from ten to 40 is calculated by adding each of the ten item scores together. Higher scores indicate stronger general self-efficacy. The reliability coefficient for the GSES is .80.

Social support. Social support is the belief that one is cared for and loved, esteemed and valued, and belongs to a network of communication and mutual obligations (Cobb, 1976). Social support can be assessed in terms of structural support (number of social ties) or functional support (function in a social group). In this study, social support was assessed by asking participants if they have ever had contact / support from a person with PD or if they have ever joined a support group. These questions were developed based on the findings from the literature review, as well as the guiding theoretical framework.

Mini-Mental State Exam. The MMSE is a questionnaire that is used to test mental status / cognition (Folstein et al., 1975). In this study, it was used as a screening tool. It is made up of 30 questions in total and each item is scored as correct or incorrect (0 – incorrect response, 1 – correct response). A total score (range: 0-30) is calculated by adding each of the 30 item scores together.

Descriptive statistics for participant demographics (e.g., age, age at diagnosis, gender, level of education, employment status, income, information needs and access) and participant scores of health literacy, self-efficacy, empowerment, and MMSE were calculated. T-tests were used for comparisons between groups (e.g., gender). Non parametric statistics were used for categorical data. Correlation coefficients were assessed using Pearson product-moment correlation coefficient. A P value of 0.05 was used to indicate statistical significance.

Data Analysis

All analyses were conducted using SPSS, Version 20.0 (IBM, 2013). Data were initially reviewed for accuracy of data input.

RESULTS

Fifty individuals volunteered to participate in the study. The demographic characteristics of the 50 participants in the study are presented in Table 1. In this sample the average age of participants was 70.52 years (SD=7.24) and participants ranged in age from 55 to 84 years at the time of study participation. Individuals with both early and late onset PD were included in the study. Of the 33 participants surveyed, 15 (45.5%) were male and 18 (54.5%) were female. The average age at diagnosis was 59.94 years (SD=11.99). The majority of participants were not employed (97%) and approximately 18 % of the participants did not complete high school. The highest level of education completed by participants was an undergraduate or post-graduate university degree (27.3%). Nearly half of participants had an income of less than \$34, 999 each year (42.4%). Health literacy profile of participants. For participants in this study the mean combined score (numeracy and prose) on the S-TOFHLA was 77.21 (SD=21.65) indicating adequate functional health literacy. The mean combined score for males was 75.4 and 78.7 for females. Participants' scores ranged from 28 to 100. Scores from the S-TOFHLA were collapsed into three broad categories of inadequate (0-53), marginal (54-66), and adequate (67-100) functional health literacy (Baker et al., 1999). In total, there were 6 (18.2%) participants with inadequate health literacy, 5 (15.1%) with marginal health literacy, and 22 (66.7%) with adequate health literacy. Approximately one third (inadequate at 18.2% and marginal at 15.1% = 33.3%) of study participants are challenged with limited functional health literacy skills.

Participant self-efficacy. Participants in this study reported as having moderately high levels of general self-efficacy (M=28.28, SD=5.9). Participants' scores ranged from 18 to 40. The mean score for males and females was 29.2 and 27.88. Mini-Mental State Exam. The mean score on the MMSE was 27.27 (SD=1.89) indicating normal cognition. Based on these scores, the researcher included all 50 participants' data in the analysis.(table 2).

Variable	Mean	SD	Cronbachs alba
S-TOFLA	32.45	6.52	.95
S-TOFLA (Nuemracy)	14.30	2.37	.65
GSES	28.48	5.9	.88

EMPOWERMENT	2.99	.28	.77
MMSE	27.27	1.89	.21

DISCUSSION

The purpose of this research study was to assess the health literacy skills and information needs of individuals managing PD and to examine the relationships of functional health literacy, self-efficacy, social support, and empowerment in this same population of north Malabar in Kerala. Participants in this study identified information related to coping with PD, PD treatment, and PD symptoms as their most important information needs. These findings are similar to previous research studies. The most commonly used sources for PD information included the Internet, healthcare professionals, and books and organizations. Proposed variables within Nutbeam's (2000) framework of functional, interactive, and critical health literacy align with improved knowledge, self-efficacy, interaction with others (e.g., social groups) and empowerment. In this study, there was a significant, positive correlation between functional health literacy and self-efficacy, functional health literacy and empowerment, and self-efficacy and empowerment. Additionally, there was a significant association between functional health literacy and social support. These findings provide support for Nutbeam's health literacy framework. Most study participants had adequate functional health literacy skills; however, approximately one third of participants scored as having marginal or inadequate functional health literacy skills. Self-efficacy can affect both health and health behaviour in many ways. For example, perceived self-efficacy can impact decision-making, as well as the amount of time and effort devoted to a particular task. In this study there was a significant, positive correlation between functional health literacy and self-efficacy. Social support can have a significant impact on health and health outcomes especially in older adults. Research studies have shown that older adults often rely on the support from family members when making health-related decisions and that social support can positively affect their overall health.

CONCLUSION

The results of this study provide support for the theoretical propositions outlined in Nutbeam's (2000) health literacy framework. Functional health literacy was positively correlated to self-efficacy and empowerment in individuals living with PD, and positively associated with social support. The findings from this study can be used in clinical practice to develop programs and services for individuals living with PD. More research is needed,

however, to better understand the proposed relationships in Nutbeam's health literacy framework.

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