Influence of disease-related knowledge and personality traits on Parkinson’s patient empowerment

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ABSTRACT

Background: Parkinson’s disease (PD), a neurodegenerative disorder, has an impact on both physical and mental functions of persons with Parkinson (PwP), who tend to lose their sense of empowerment, cognitive state of perceived competence and perceived control. A diminished sense of empowerment is a result of being dependent and unable to have control over their own lives and health. Objectives: This study aimed to examine the influence of disease-related knowledge and personality traits on empowerment of PwP. Methods: This was a cross-sectional survey by a purposive sample of 128 PwP. Participants were interviewed with questionnaires: (1) Parkinson’s patient empowerment, (2) Health locus of control, (3) Self-esteem, and (4) Parkinson’s disease related knowledge-related-knowledge. Results: Participants had mean age and disease duration of 58.3 ± 8.9 years, and 8.1 ± 4.8 years, respectively. Parkinson’s patient empowerment showed a significant positive relationship between variables such as self-esteem (r = 0.48, P < 0.001), internal health locus of control (IHLC) (r = 0.50, P < 0.001), external locus of control by powerful others (PHLC) (r = 0.32, P < 0.001), and self-care knowledge (r = 0.16, P = 0.039). There was a negative relationship between HY staging (r = −0.18, P = 0.023) and Parkinson’s patient empowerment. A significant regression equation was found (F(8, 119) = 10.68, P <0.001), with an adjusted R^2 = 0.38. The multiple regression results revealed that self-esteem (β = 0.33, P < 0.001), IHLC (β = 0.29, P = 0.001), PHLC (β = 0.21, P = 0.014), and self-care knowledge (β = 0.18, P = 0.023) were significant influencing factors on Parkinson’s patient empowerment. Conclusions: Self-care knowledge, self-esteem, IHLC, and PHLC were four significant influential factors on Parkinson’s patient empowerment. Three proposed non-pharmacological treatment strategies to increase Parkinson’s patient empowerment were (1) Education interventions to focus on self-care knowledge, (2) Cognitive interventions to enhance patients’ feelings of self-worth and the beliefs of patients’ health influenced by their own behaviors, and (3) Strengthening patient-doctor relationship to enhance patients’ feelings of trust and to cooperate with doctors.

INTRODUCTION

The concept of empowerment in health care came from self-management, involving patients to have responsibilities to manage their own health and gain control over their own lives, which finally improves the health outcomes [1,2]. The patient empowerment idea also has been used as a proactive partnership and patient self-care strategy to improve health outcomes and the quality of life in patients with chronic conditions [3-10] such as diabetes, end-stage renal disease, HIV, chronic obstructive pulmonary disease, osteoporosis, cancer, and mental disorders.

We adopted the empowerment concept in health care context and individual psychological perspective called “empowerment” and referred to as psychological health empowerment. Based on Zimmerman and Menon’s empowerment concepts [11-13], empowerment in our study was defined as a cognitive state characterized by a sense of perceived control and perceived competence to manage one’s own health. Perceived competence refers to the beliefs about one’s ability to perform the roles and responsibilities of taking care of one’s own health. Perceived control refers to the beliefs about one’s ability to make a decision related to one’s own health.

Parkinson’s disease (PD), a chronic disorder characterized by neurodegeneration, affects both physical and mental functions of persons with Parkinson (PwP). The disease...
is characterized by motor symptoms such as slowness of movement, rigidity, resting tremor, and postural imbalance. Besides motor symptoms, patients also experience non-motor symptoms (NMS) such as autonomic dysfunction, pain and sensory disturbances, sleep and mood disorders, and dementia [14]. The estimated number of PD population in Thailand was 60,565 cases based on PD registry in Thailand launched for 2 years of data [15]. Most of the PwP in Thailand are treated by general practitioners or internists without specialty training in neurology. The Kingdom of Thailand has 67,228,562 populations [16]. However, there are only 278 board-certified neurologists in Thailand which is not enough to serve Thai populations. In addition, most PD specialists work in university hospitals and the specialized PD tertiary clinics are in major cities. Thus, most Thai PwP in remote areas could not reach the specialist care they need and suffer from the long waiting lists of 2 years to be referred to the specialized center [17].

The majority of Thai population are in three national health insurance schemes, Civil Servant Medical Benefit Scheme (CSMBS), Social Security Insurance (SSI), and the Universal Coverage Scheme (UC scheme). Thai people under these three major schemes are allowed to reimburse only basic Anti-Parkinsonian medications in the essential drug lists. New PD medications such as levodopa intestinal gel injection, apomorphine infusion, and rotigotine transdermal patch are available in PD specialized tertiary care centers and requires out of the pocket payment from patients.

The previous study in Thailand [18] indicated that the burden of PD caregivers in both spousal caregivers and offspring caregivers was obvious and increased when PwP developed severe disabilities and felt depression and anxiety. PwP in Thailand also have the psychosocial problems similar to PwP in other countries [19-21]. There was no research studies how people in the society view PwP in Thailand. However, based on the “Colorful Tulips” book of Thai PwP testimonials [22], 16 Thai PwP shared the real stories of their lives with PD. They expressed their insight feelings that most of people in the society still do not understand about PD. This made PwP feel lonely, depressed and anxious. They did not want to go out and do social activities with their loved ones because of the eyes of people around them and questions from society related to their appearances such as shaking, slow movement, no facial expressions, drooling, and other PD-related symptoms. Therefore, the feelings of PwP lose self-worth or loving oneself [35]. The link between self-esteem and patient empowerment is possibly related to the feelings of being responsible for one's own life or health. Individuals with low self-esteem do not perceive themselves as valuable persons and tend to feel anxious, depressed and unhappy as a result of not being able to make decisions for changes to their lives [32,36]. Individuals with high self-esteem look at themselves as able to change their lives for the better, as being responsible for their health, giving attention to their own health and making their own health choices [32,36]. Health locus of control is defined as a generalized expectation of the relationship between an individual's behavior and health outcomes [37]. The health locus of control consists of an internal health locus of control (IHLC), an external health locus of control by chance (CHLC) and an external health locus of control by powerful others (PHLC). The term “IHLC” means people believe that their own actions have a certain impact
on their health. “External locus of control by chance” means people believe that their own health is influenced by chance or fate or the gods. “External locus of control by powerful others” means people believe that their own health is dependent on the competence of doctors, and/or on behavior of their friends and family. Patients with an external locus of control do not perceive their own actions as significantly influencing their health [34]. They also have worse habits and are less likely to perform health promoting behaviors, and ignore messages regarding disease prevention or illness recovery [34]. Meanwhile, people with IHLC tend to adopt more appropriate behaviors to take care of their health than people with external locus of control [11,37]. These intrinsic factors inside patients must be considered for improving patient empowerment to get better health outcomes.

Therefore, this study aimed to examine the influence of PD-related knowledge (PD, treatment, and self-care knowledge) and personality traits (self-esteem and health locus of control) as shown in the conceptual framework Figure 1.

**METHODS**

**Study Deign and Population**

This was a cross-sectional survey study (6-month period; September 2014-February 2015) at Chulapd. The sample size was determined by Jacob Cohen's formula for multiple regression analysis [38]. A medium effect size is most commonly used when no research is available to assess the population effect size [39]. Replacing all variables with the number of independent variables = 7, the medium effect size [40] = 0.15 and L value for the desired alpha (0.05) and power (0.85) = 16.04. As a result, the minimum sample size requirement was 114 PwP, inclusion criteria were as follows: (1) Diagnosed with PD, (2) No visual and auditory hallucination, (3) A minimum score of 24/30 on mini mental status examination, and (4) Ability to understand and complete the questionnaires. Taking into the account the inclusion criteria and two operating days of PD clinic (Tuesday afternoon [13.00 p.m. - 16.00 p.m.] and Wednesday morning [9.00 a.m. - 12.00 p.m.]), the researcher was able to interview 5-8 PwP per week for 6 months. The final sample size was 128 PwP after the end of data collection period.

**Data Collection**

PwP were purposively sampled based on inclusion criteria by screening out patient's records at the PD clinic at Chulalongkorn Hospital. The data were collected by only one researcher interviewing PwP regarding each question on the questionnaire. The interview period was approximately 30 min for each patient.

**Measurement Tools**

The questionnaires were tested on 18 PwP before conducting the survey. It consisted of four measurement tools in the form of summed 5 points Likert-type scales in Parkinson's patient empowerment, health locus of control, self-esteem and yes–no questions in PD-related knowledge.

**Parkinson's patient empowerment**

This measurement was developed from Menon [11] and diabetes empowerment scale [41] to measure empowerment in PwP. The final version of the questionnaire contained 14 items, which were treated as unidimension for perceived control (5 items) and perceived competence (9 items) with Cronbach's alpha 0.90.

**PD-related knowledge**

This measurement was developed using knowledge contents based on a previous study and clinical practice guideline [42,43]. The final version of PD knowledge contained 26 items with rKR-20 = 0.61, which covered knowledge of disease (7 items), treatment (11 items), and self-care (8 items).

Both measurement tools for Parkinson's patient empowerment and PD-related knowledge were tested for validity with the index of item-objective congruence (IOC method) by five experts (one movement specialist, two neurologists, one PD psychiatrist, and one neuro-pharmacist) to modify or delete items if they lacked clarity. All experts were asked to rate each item's relevance in measuring Parkinson's patient empowerment by choosing “clearly measuring” (score = +1), “unclear” (score = 0), and “clearly not measuring” (score = −1). After the ratings from all experts, the selection of each item was converted into scores and then computed for the average scores as IOC scores. The cut point or index of IOC was determined as the criteria for the selection of each item in the questionnaires. The scores above the cut point or index of IOC were included in the questionnaires. In this study, the IOC scores from five experts which were above 0.5 were selected as an item for the questionnaires. Each item was also reviewed for content, grammatical correctness, organization, readability, and clarity.

**The multidimensional health locus of control scale Form B**

The measurement has been adopted from Thai standardized translation questionnaires [44], developed by Wallston [37]. The final version consisted of 18 items used to assess an individual's belief about what influences health, which measures three discrete dimensions. An 18 items measure was IHLC (6 items), CHLC (6 items), and PHLC (6 items) with Cronbach's alpha 0.68.

**Self-esteem**

Thai standardized translation questionnaire [45], developed by Rosenberg [35], was used to measure self-esteem in this study. This measurement included 10 questions with Cronbach's alpha 0.83.
Statistical Analysis

The descriptive statistical analysis was used to describe the demographic data of samples. Student’s t-test was used to compare empowerment between groups. Kruskal-Wallis test was also used to analyze the nonparametric test for comparing more independent samples with different sample sizes. Multiple regression analysis with ENTER method was performed to identify the influence of PD-related knowledge and personality traits on Parkinson’s patient empowerment. Variance inflation factor (VIF) was calculated to ensure that there was no multicollinearity. Associations between Parkinson's patient empowerment and all related variables were explored by means of the Pearson correlation coefficient. A $P < 0.05$ (two-tailed) was considered to be statistically significant. Statistical analyses were performed using the SPSS version 17.0 software (SPSS Inc., Chicago IL).

Ethical Approval

The study protocol received ethical approval from the Institution Review Board of Faculty of Medicine, Chulalongkorn University (IRB No. 509/56). Informed consent was received from each PD patient before conducting the interview.

RESULTS

A total of 128 PwP (61 males and 67 females) were included in the study. Patients’ mean age was 58.3 years (SD = 8.9; range 37-81). According to education level, 57.0% of patients held bachelor's degree or above and 43.0% of patients had educational achievements less than bachelor's degree. The duration of disease reported by patients was 8.1 ± 4.8 years. There were no significant differences of empowerment scores in different gender, education level, marital status, caregivers, caregiver relationship, and family income groups (Table 1). However, we found Hoehn and Yahr staging was significantly negatively correlated with empowerment ($r = -0.18, P = 0.04$) (Table 1). Therefore, Hoehn and Yahr staging (HY stage), scale of the severity of PD in the motor functions and evaluation of the patterns of progressive motor impairment [46], was included for controlling the severity of disease in the multiple regression analysis. To recalculate the sample size, all variables with the number of independent variables = 8, the medium effect size = 0.15 and L value for the desired alpha (0.05) and power (0.85) = 16.77. The required sample size was 120 PwP. Thus, the data collection of 128 PwP at the beginning before including HY stage provided enough power in the analysis.

IHLC and Self-esteem were strongly positive correlated with Parkinson’s patient empowerment, $r = 0.50$ and 0.48, $P < 0.001$, respectively (Table 2). PHLC was moderately positively correlated with Parkinson’s patient empowerment, $r = 0.32$, $P < 0.001$. Self-care knowledge was small positively correlated with Parkinson’s patient empowerment, $r = 0.16$, $P = 0.039$. IHLC and PHLC were moderately positive correlated, $r = 0.41$, $P < 0.001$. Tabachnick and Fidell's suggested that a bivariate correlation more than 0.7 should not be included in multiple regression analysis [47]. In addition, we did not drop any of them or use factor analysis to combine them because, theoretically, they have a sense of their own.

Multiple regression analysis was utilized including all possible influential independent variables (PD knowledge, treatment knowledge, self-care knowledge, self-esteem, IHLC, CHLC, and PHLC). There were no multicollinearity problems among influential variables according to VIF and tolerance analysis as shown in (Table 3). Using the enter method, all variables explained 38% significant amount of variance in Parkinson’s patient empowerment ($F(8, 119) = 10.68, P < 0.001, R^2 = 0.42, R^2_{Adjusted} = 0.38$). Self-esteem, IHLC, PHLC, and self-care knowledge were significant and positive influencing factors on Parkinson’s patient empowerment. These findings mean that PwP with high self-esteem, IHLC, PHLC along with high self-care knowledge have better empowerment (Table 3).

DISCUSSION

The key findings of the study indicated that self-esteem, IHLC, PHLC, and self-care knowledge were the important influencing factors on Parkinson’s patient empowerment. Therefore, both personality traits and PD-related knowledge were considered to be mutually important factors on Parkinson’s patient empowerment.

According to the correlation and descriptive statistical analysis for demographic variables and Parkinson’s patient empowerment, we found only HY staging, indicating the severity of PD in the motor functions and evaluation of the patterns of progressive motor impairment, was significantly negatively related with Parkinson’s patient empowerment. The progression of PD through HY stages was correlated with motor decline, decline in the quality of life and neuroimaging studies of dopaminergic loss [48]. Thus, the worse PD symptoms possibly lowered a sense of empowerment in PwP.

Based on the findings of this study, even though the samples of our study were PwP, our findings, like other studies [12,32,34,36,49] showed that personality traits such as self-esteem and IHLC were essential influencing factors on empowerment, which can drive individual behaviors. Spreitzer's study reported self-esteem was significantly related to psychological empowerment because it impacts how individuals see themselves as valuable people to change for positive behavior in their work and organization [32]. Patients with high self-esteem give attention to their own health, and they believe in their ability to perform the role and responsibilities of taking care of their own health due to their feeling of value and self-worth [36]. Meanwhile, HLC was also another important factor which affects empowerment. Patients with IHLC believe that their own actions have a certain impact on their health and they can change their risk behaviors to perform more healthy behaviors [34,49]. Patients with IHLC have better health habits and they are more likely to adopt good health behaviors, and a result gains better health status than people with external health locus of control [11,37]. However, this study discovered that PHLC was also an important factor which positively affected Parkinson’s patient empowerment. Regarding the unique characteristics of PD, as the disease progresses, patients suffer from some physical limitations and basic activities of daily living, resulting in the need for close caregiving from people around them [18]. Although patients with external health locus of control are expected to have
low empowerment, there are some different health behaviors between patients with PHLC and CHLC. Wallston's study [49] illustrated that patients with PHLC highly trust their own physicians and tended to be active information seekers, participating in education programs and taking medications according to physicians’ advice. When patients with PHLC have
illness or something wrong with their health, they will seek care for their illness. On the other hand, patients with CHLC tend to delay seeking care for their illness. We assumed that the respect for medical professionals from patients with PHLC could possibly have an indirect impact on the empowerment of PwP in a positive relationship.

The previous studies [26-29,50] showed that knowledge is important in a patient education program to enhance patient empowerment. Our results showed only self-care knowledge was an essential positive factor on Parkinson's patient empowerment. Disease and treatment knowledge was a basic knowledge in self-care knowledge as mentioned in the studies [26-29]. Both disease and treatment knowledge did not directly impact on Parkinson’s patient empowerment. However, empowered patients who participated in education programs should have a basic knowledge of disease and treatment which make patients adopt self-care knowledge from the program. Therefore, the introduction of PD education program to empower PwP still required basic information of disease and treatment before providing self-care knowledge to PwP. As a result, PwP with low self-esteem, IHLC, and PHLC were suggested to add more self-care knowledge to increase their empowerment.

Self-care knowledge can empower PwP because it also contains the knowledge such as self-monitoring through PD diary, practical exercise, anxiety and stress management, and etcetera, which PwP can apply to solve psychosocial problems as shown in PD empowerment programs in European countries [50-52]. Thus, the self-care knowledge is important to empower PwP. Many studies [50-52] identified the objectives of program that empowered Parkinson’s patients were to develop psychosocial skills which not specific to disease or treatment knowledge. Our results confirmed PwP in Thailand also needs the PD education program, complementing the medical treatment, to assist in the management of psychosocial problems in PwP along with the self-care knowledge.

Pharmacological and surgical treatment for PD in Thailand has been dramatically improved for PwP [53]. The findings from this study will contribute the additional care and non-pharmacological treatment for PwP in Thailand and provide the insights of intrinsic factors such as self-esteem, HCL, and PHLC and Parkinson’s patient empowerment which health care providers need to be aware of, to develop the strategies to empower Parkinson’s patients. Implications of research findings suggested three non-pharmacological treatment strategies to enhance empowerment through self-esteem, IHLC, PHLC, and self-care knowledge.

First, education interventions to focus on self-care knowledge: Based on the self-care knowledge results, PD education interventions must emphasize on PD exercise, food and nutrition, stress management and self-monitoring for PD symptoms and recording of PD medication side effects. Due to the burden among PD caregivers [39,44-46], the involvement of caregivers in PD education program will assist not only PwP but also caregivers to share the compassionate feelings toward each other and strengthen the relationship between patients and caregivers. Therefore, the previous studies [51,54] suggested to also involve caregivers in PD education program.

Second, cognitive interventions to enhance the feelings of self-worth or loving themselves (self-esteem) and the beliefs of patients that their health is influenced by their own behaviors or actions (IHLC): The cognitive interventions will be able to increase IHLC; change their negative core beliefs about themselves into positive new beliefs about themselves; and modify beliefs that individuals hold about how much they can control their health outcomes. This would finally enhance Parkinson’s patient empowerment. This is similar to the previous studies [55,56] using cognitive behavioral therapy designed especially for low self-esteem to assist depression and anxiety symptoms in patients. Health care providers might help PwP to identify their negative thought patterns, aid them to interrupt these thought patterns and replace them with more positive ones.

Finally, strengthening patient-doctor relationship: As mentioned before about PwP with PHLC, the strong relationship between doctors and patients will possibly empower patients because PwP with PHLC tend to have a high trust and follow the recommendations from the doctors [49]. However, it requires the new roles of doctors to strengthen the relationship with patients to shape the behaviors and attitudes of patients in ways that empower patients [57]. The new roles of doctors are a new paradigm shift to allow patients to be in

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*Statistically significant (P<0.05), IHLC: Internal health locus of control, CHLC: External health locus of control by chance, PHLC: External health locus of control by powerful others

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Table 3: Summary of multiple regression results for all influencing variables on Parkinson's patient empowerment (n=128)

<table>
<thead>
<tr>
<th>Model</th>
<th>Unstandardized coefficients</th>
<th>Standardized coefficients</th>
<th>Collinearity statistics</th>
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<tbody>
<tr>
<td></td>
<td>B</td>
<td>Standard error</td>
<td>Beta</td>
</tr>
<tr>
<td>(Constant)</td>
<td>16.41</td>
<td>7.646</td>
<td></td>
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<tr>
<td>Self-esteem*</td>
<td>0.40</td>
<td>0.10</td>
<td>0.33</td>
</tr>
<tr>
<td>Disease knowledge</td>
<td>-0.21</td>
<td>0.48</td>
<td>-0.03</td>
</tr>
<tr>
<td>Treatment knowledge</td>
<td>-0.37</td>
<td>0.28</td>
<td>-0.10</td>
</tr>
<tr>
<td>Self-care knowledge*</td>
<td>1.42</td>
<td>0.62</td>
<td>0.18</td>
</tr>
<tr>
<td>IHLC*</td>
<td>0.62</td>
<td>0.18</td>
<td>0.29</td>
</tr>
<tr>
<td>CHLC</td>
<td>-0.05</td>
<td>0.13</td>
<td>-0.03</td>
</tr>
<tr>
<td>PHLC*</td>
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<td>0.21</td>
</tr>
<tr>
<td>HV stage</td>
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<td>0.75</td>
<td>-0.08</td>
</tr>
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</table>
a partnership in health and health care. The doctors will act as coaches who provide informed advice and allow patients to be responsible for their own health. However, it might require doctors to listen carefully to the voices of patients, treat patients with respect and build a bond with patients to improve their health.

**Limitation of the Study and Further Studies**

The first limitation of our study is the first modified patient empowerment measurement tool in PwP based on Menon’s psychological health empowerment model, which possibly requires more psychometric tests. Second, it was the limitation of the generalizability to other populations. However, we selected PwP at PD center at King Memorial Chulalongkorn Hospital because it was the first well-established PD center in Thailand. There is still number of PwP who are not able to access the PD treatment or even do not know they have PD in Thailand. Further studies should include this PwP. The last limitation of the study is the multiple regression methods which have a weakness of measurement error. It only allows the measurement error in a dependent variable while the assumption of multiple regression analysis said no measurement error in independent variables. However, it is powerful tools to predict and explain the causal influence on a population outcome. With the time limitation of data collection, the sample size in this study was too small to perform advanced statistical analysis such as structural equation model which can reduce measurement error in independent variables.

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