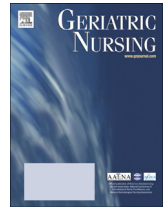




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## Feature Article

## Predictive model for health-related quality of life in patients with Parkinson's disease

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## ABSTRACT

This study was conducted to develop and test a prediction model that explains health-related quality of life (HRQoL) of patients with Parkinson's disease (PD). Participants were 248 patients with PD enrolled in the neurology clinic of a university hospital in Seoul, Korea. The data were collected through structured questionnaires from March 1 to July 5, 2013. Motor fluctuations, depression, sleep disturbances, fatigue, and activities of daily living had significant direct effects on the quality of life of PD patients. Disease severity, social support, pain, sleep disturbances, fatigue, and activities of daily living had significant indirect effects on patients' quality of life. These predictive variables explained 77.4% of the total variance. The assessment of HRQoL in PD should be considered along with the variables affecting it, including social support. In addition, strategies to enhance social support may be useful for improving the quality of life for patients with PD.

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## Introduction

Parkinson's disease (PD) is a chronic neurodegenerative disorder characterized by tremors, rigidity, and bradykinesia.<sup>1</sup> The definite cause of PD has not been identified, and it is assumed that PD occurs due to a combination of genetic and environmental factors.<sup>2</sup> Patients with PD experience various motor and non-motor symptoms.<sup>1,3,4</sup> Motor symptoms include tremors, rigidity, bradykinesia, speech and gait disturbances and postural instability, while non-motor symptoms include depression, anxiety, constipation, pain, sleep disturbances and fatigue.<sup>1,3,4</sup> Since there is no cure for PD, several treatment modalities have been employed, including medical treatment, surgical treatment and exercise therapy, in attempts to alleviate these motor and non-motor symptoms.<sup>1</sup>

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PD patients have difficulty performing their daily activities due to symptoms such as bradykinesia, gait disturbances and stiffness, and their social activities are limited.<sup>5,6</sup> These difficulties, along with the suffering caused by the long duration of the illness, can result in a poor quality of life (QoL) for PD patients.<sup>6</sup> Given the chronic and incurable nature of PD,<sup>1,2</sup> a patient's QoL is considered to be an important outcome variable in assessments of his/her health status, along with its therapeutic effect, thus treatments are focused on alleviating symptoms or slowing the progression of the disease.<sup>7</sup>

Many studies of QoL have been conducted and factors related to QoL have been identified in patients with PD.<sup>5,7–9</sup> Motor symptoms and motor fluctuations negatively affect activities of daily living (ADL) and concurrent QoL,<sup>7–9</sup> thus disease severity may impair QoL.<sup>5,7</sup> Non-motor symptoms such as sleep disorders, fatigue, depression, and pain appear in all stages of PD<sup>10</sup> and reduce QoL.<sup>11,12</sup> The frequency and severity of these symptoms increase as PD progresses.<sup>11–14</sup> In addition, it has been reported that non-motor symptoms have a more significant influence on QoL than motor symptoms and disabilities.<sup>11</sup> Depression is the most common non-motor PD symptom, as it is experienced by more than 50% of PD

patients.<sup>12</sup> Pain is associated with rigidity, muscle spasm, and dystonia in patients with PD.<sup>13</sup> Since pain is likely to be overlooked by family doctors and medical specialists, it may be a more common symptom than is usually considered by health care providers.<sup>15</sup> Sleep disturbances in a variety of forms are experienced by 96% of patients, and patients may experience several types concurrently (e.g., insomnia and sleep fragmentation).<sup>16,17</sup> Fatigue is a symptom experienced by 33–58% of patients, and may affect their ability to maintain their daily activities, relationships with others, social roles and other tasks.<sup>18</sup> In addition, fatigue affects QoL by adding functional impairment to physical impairments caused by bradykinesia, rigidity and gait disturbance.<sup>14,18</sup>

Most of the previous studies on QoL in PD patients have examined the relationship between QoL and some factors and identified factors that affect QoL, including several factors.<sup>5,8,11,12</sup> In addition, the influence of some factors were consistently reported in studies of QoL, but some factors were not consistent in previous studies. Depression is a strong determinant of QoL in many previous studies.<sup>12,19,20</sup> While there have been reports that both motor and non-motor symptoms affect QoL in patients with PD,<sup>7,9,20</sup> some studies have shown that non-motor symptoms have a greater impact on QoL than motor symptoms.<sup>12,21</sup> There was also a study that showed patient functional status directly affected QoL,<sup>8</sup> while some showed function was not related to QoL.<sup>5</sup>

In PD patients, motor problems make it more difficult to perform independent daily activities as the disease progresses,<sup>6</sup> so patients become more physically and emotionally dependent on others over time.<sup>22</sup> Therefore, many patients require physical and emotional support from care providers,<sup>22</sup> and social support may be an important factor in the QoL of patients with PD. In addition, it has been reported that marital status affected QoL in PD patients and the QoL of patients with spouses was higher than that of patients without spouses in a previous study.<sup>21</sup> Although the influence of social support on the QoL of patients with chronic illnesses has already been reported,<sup>23</sup> the association between social support and QoL in PD patients has rarely been studied. Therefore, it is necessary to identify the influence of social support on QoL in PD patients.

Recently, reports on comprehensive and structural models of the QoL of PD patients have been published; however, these studies did not include environmental factors such as social support.<sup>5,8</sup> Therefore, we sought to develop and test a predictive model to explain QoL in PD patients, including social support as an environmental factor that can affect QoL and other factors related to QoL, based on a literature review.

### Conceptual framework and hypothetical model

The conceptual framework of this study was based on a literature review and previous study results. Individual characteristics, environmental characteristics, physiological and biological factors, symptoms, and functional status affect subject QoL.<sup>24</sup> Individual characteristics affect symptoms, functional status and QoL, and social support affects QoL as an environmental characteristic.<sup>24</sup> In particular, health-related quality of life (HRQoL) in chronic illnesses is directly related to the individual's health, and the QoL can be considered in the context of health, function, emotional well-being and social roles.<sup>25</sup> Therefore, we developed a conceptual framework in which disease-related characteristics (including the severity of PD and motor fluctuations), environmental characteristics (including social support) known to affect cognitive and emotional status (including depression and pain) in the course of the illness and treatment and physical status (including sleep disturbances, fatigue and ADL) were included.<sup>24,25</sup> Since severity of PD and motor fluctuations have been reported in many previous studies as disease-related characteristics that affect QoL,<sup>5,7–9,21,26</sup> we included PD severity and motor fluctuations as disease-related characteristics. Social support was the main environmental characteristic that was considered to affect QoL in chronic illness.<sup>23</sup> Depression and pain, which are non-motor symptoms, are cognitive and emotional factors that significantly affect the QoL of patients with PD,<sup>5,9,19,20</sup> therefore, depression and pain were set as cognitive and emotional status in this study. Sleep disturbances, fatigue, and ADL in patients with PD were also reported to be factors affecting QoL,<sup>8,9,12,25,27</sup> thus we added sleep disturbances, fatigue, and ADL as physical status. In addition, cognitive and emotional status and physical status influence each other.<sup>5,7,8,12–14,27</sup> Therefore, the hypothetical model of this study consisted of three exogenous variables and six endogenous variables, based on the conceptual framework for path setting. The exogenous variables included the severity of PD, motor fluctuations and social support, and the endogenous variables included depression, pain, sleep disturbances, fatigue, ADL and QoL (See Fig. 1).

### Aim

The aims of this study were 1) to develop and test a prediction model (path model) to explain HRQoL in PD patients including social support and 2) to identify the direct and indirect effects of the variables affecting PD patient QoL.

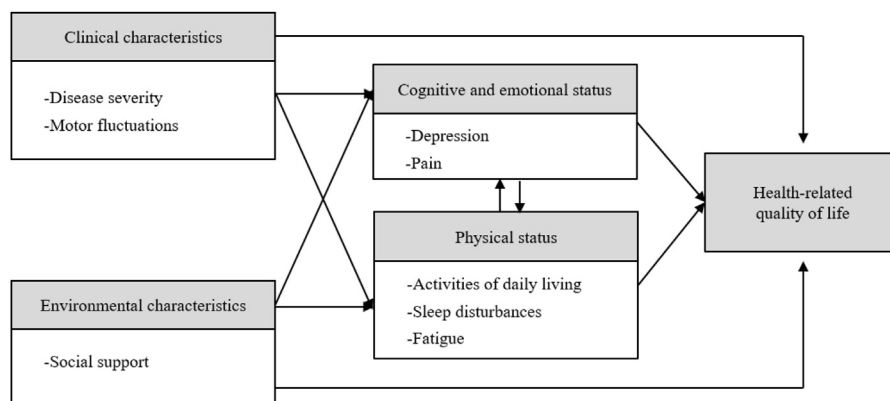


Fig. 1. Conceptual model for health-related quality of life in patients with Parkinson's disease.

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