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## Analysis of University of California in San Francisco (UCSF) Symptom Management Theory and Theory Implication for Persons with Neurological Disorders/Diseases

### Analiza teorii zarządzania objawami stworzonej przez Szkołę Pielęgniarską Uniwersytetu Kalifornijskiego w San Francisco (UCSF) i implikacje tej teorii dla osób z chorobami neurologicznymi

Klaudia Cwiekala-Lewis<sup>1</sup>, Brandon H. Parkyn<sup>2</sup>, Kinga Modliszewska<sup>2</sup>

<sup>1</sup>University of Phoenix, College of Health Sciences and Nursing, USA

<sup>2</sup>Translate Nursing LLC, USA

#### Abstract

**Introduction.** According to the World Health Organization (WHO), in 2015 neurological disorders accounted for 12% of total deaths worldwide. Presented data demonstrates that neurological neuropsychiatric disorders (NND) cause a substantial burden on global health. A majority of neurological disorders are progressive and currently have no cure.

**Aim.** Is to evaluate current evidence of a middle range theory of Symptom Management Theory (SMT) created by University of California in San Francisco (UCSF) School of Nursing and to analyze implication of the theory for persons with NND.

**Material and Methods.** Systematic review of the literature will be presented. SMT will be analyzed and evaluated based on Walker and Avant with special consideration to theory utilization in research encompassing NND. Study quality was assessed using the Quality Index (QI) checklist developed by Downs & Black in 1998.

**Results.** A total of seven articles was included to support empirical relationships between SMT components evidenced in studies involving adults with neurological disorders/diseases. Overall, the literature supports SMT as a theoretical framework for symptoms management for persons with neurological disorders/diseases.

**Conclusions.** The SMT is still in experimental stages. Analysis of the SMT proved that the theory is parsimonious, logical in its adequacy and may be generalized to other studies. This review created a solid beginning to explore recommendations to promote standards for symptom management in future investigations of NND. Further research is needed involving measurement of symptoms of multidimensional symptom management with persons with NND. (JNPN 2017;6(2):55–65)

**Key Words:** Symptom Management Theory, neurological disorders/diseases, nursing, theory

#### Streszczenie

**Wstęp.** Światowa Organizacja Zdrowia (WHO) podaje, że w 2015 r. zaburzenia neurologiczne stanowiły 12% wszystkich zgonów na całym świecie. Przedstawione dane wskazują, że neurologiczne zaburzenia neuropsychiatryczne (NND) powodują znaczne obciążenie dla zdrowia i gospodarki na świecie. Większość zaburzeń neurologicznych jest o charakterze progresywnym i obecnie nie ma lekarstw na ich leczenie.

**Cel.** Głównym tematem tej pracy jest ewaluacja aktualnych danych w zakresie teorii średniego zasięgu w ujęciu teorii zarządzania objawami (SMT) stworzonej przez Szkołę Pielęgniarską Uniwersytetu Kalifornijskiego w San Francisco (UCSF) oraz analiza wpływu tej teorii na pacjentów z neurologicznymi zaburzeniami neuropsychiatrycznymi (NND).

**Materiał i metody.** Badanie oparte jest na systematycznym przeglądzie piśmiennictwa, którego główne wnioski zostaną zaprezentowane. Teoria zarządzania objawami (SMT) będzie przeanalizowana i oceniona w oparciu o procedurę stworzoną przez Walker'a i Avant'a ze szczególnym uwzględnieniem wykorzystania powyższej teorii w badaniach

obejmujących neurologiczne zaburzenia neuropsychiatryczne (NND). Standard i jakość badania oceniano stosując wskaźnik jakości (QI) opracowany przez Downs i Black w 1998 r.

**Wyniki.** Badanie zostało oparte o wnioski z siedmiu artykułów uzasadniających empiryczne relacje między elementami teorii zarządzania objawami (SMD) oraz o dane potwierdzone w badaniach z udziałem dorosłych pacjentów z chorobami/zaburzeniami neurologicznymi. Podsumowując, literatura specjalistyczna potwierdza założenia zawarte w teorii zarządzania objawami (SMT) i uznaje je, jako teoretyczne ramy dla zarządzania objawami dla osób z chorobami/zaburzeniami neurologicznymi.

**Wnioski.** Teoria zarządzania objawami (SMT) jest wciąż w fazie eksperymentalnej. Analiza tej teorii potwierdziła, że teoria jest oszczędna w kosztach, logiczna w jej adekwatności i może być zastosowana w innych badaniach. Powyższe badanie stworzyło solidny początek ku dalszym badaniom w tej tematyce. Autorka postuluje by w kolejnym stopniu zalecić szczegółowe badania by kolejno rozwijać zalecenia i promować nowatorskie standardy zarządzania objawami w przyszłych badaniach nad neurologicznymi zaburzeniami neuropsychiatrycznymi (NND). Autorka podkreśla konieczność dalszych badań obejmujących pomiar objawów w zakresie leczenia objawowego pacjentów z neurologicznymi zaburzeniami neuropsychiatrycznymi w wielowymiarowej skali. (PNN 2017;6(2):55–65)

**Słowa kluczowe:** teoria zarządzania objawami, choroby neurologiczne, teorie pielęgniarstwa

## Introduction

According to the World Health Organization (WHO), in 2015 neurological disorders accounted for 12% of total deaths worldwide. Within that number WHO states that neuropsychiatric disorders will account for 0.21% of total deaths due to epilepsy, Alzheimer's and other dementias will claim 0.81% of total deaths, Parkinson's Disease (PD) will account for 0.20% of the total deaths and Multiple Sclerosis (MS) will claim 0.03% of total deaths. Presented statistical data demonstrates that neurological neuropsychiatric disorders (NND) cause a substantial burden on global health. NND causes more deaths than diseases such as digestive and respiratory diseases, as well as malignant neoplasm [1]. A majority of the above mentioned NND are progressive and currently have no cure. Medication and treatment are utilized to manage disease symptoms, not to provide a cure.

The purpose of this paper is to evaluate current evidence of a middle range theory of Symptom Management Theory (SMT) created by University of California in San Francisco (UCSF) School of Nursing and to analyze implication of the theory for persons with neurological disorders/diseases. Because neurological neuropsychiatric diseases have such a huge impact on global health and since the current treatments mostly provide symptom management, Symptom Management Theory (SMT) should be utilized to guide standards of practice. The SMT is a middle range theory that was created by University of California in San Francisco (UCSF) School of Nursing. The SMT describes and explains a specific phenomenon, an individual's experience of symptoms, and its related concepts. As a theory, SMT has been revised and progressed to its use in a multitude of research studies examining a wide variety of illnesses and conditions. The SMT's three main concepts of symptom experience, symptom

management strategies and symptom outcome have been clarified and verified [2,3]. It has demonstrated consistency and validity throughout its use among various types of patient populations, symptoms, conditions and disease stages, and strategies [3]. Furthermore, it has demonstrated usefulness and applicability in diverse nursing practice settings.

The SMT is one of the most recently developed and revised theoretical models and should be subject to analysis. Analysis will allow thorough examination of the strengths and weaknesses of the SMT. The theory's potential strengths could lead nursing research and standards of practice, whereas identified weaknesses create opportunities for further theory modification and testing. This analysis could also support its usefulness in its application within patients with neurological disorders/diseases [4].

### *Research Question*

Symptom Management Theory incorporates three main concepts of symptom experience, symptom management strategies, and symptom status outcomes could this theory provide theoretical framework for symptoms management for persons with neurological disorders/diseases?

### *Symptom Management Theory*

SMT was originally published at UCSF and later revised in 2001 to include the domains of nursing science. The central concepts of the University of California School of Nursing (UCSF) symptom management theory revolves around three central concepts: symptom experience, symptom management and symptom outcomes [2]. As Larson and colleague describes the symptom experience, they mention that to have a

symptom there are multiple aspects involved with how that symptom is experienced and handled. The perception of the symptom includes the person's recognition of a symptom in the first place. Perception could also be influenced by the environment as well as individual patient's characteristics including physiological, psychological and contextual factors.

The update revision by Dodd and colleague [5], included the three domains of the nursing paradigm: person, environment and health. Furthermore Dodd and colleague expanded the components of symptom management strategies to ask, who, what, how, when, to whom, where, how much, and why a strategy was employed. The central theme of the theory focuses on the patients' experiences from their own perspective. The theory hypothesized that subjective experiences cause patients the most distress [3].

The original model indicated that all of the central concepts work with each other in a bidirectional circular manner and all have an effect on each other. The updated model represents multi-dimensional circular manner with added outcome of financial cost, health and employment related costs, costs of poorly managed symptoms, and other costs associated with the patient's life [5]. The theory also suggests that the nurse should seek understanding of the impact of symptom experience from the patient's perspective so that symptom management can be successful.

### *Process of Analysis*

Walker and Avant's [4] framework was used as an analysis of the Symptom Management Theory. This framework includes seven steps that include the theory's origins, meaning, logical adequacy, usefulness, generalizability, parsimony, and testability of the theory. This would provide a concise and systematic method to enable further development and modification of the presented theory.

## **Walker and Avant Framework for Analysis of the Symptom Management Theory**

### *Origins*

Symptom management theory (SMT) was created by the faculty of the University of California in San Francisco (UCSF) School of Nursing. The theory's three main concepts include symptom experience, symptom management strategies and symptom status outcomes. The central concepts of The SMT which were further extended by Dodd and colleague [5], emphasizes that the model should include the three domains of the

nursing paradigm, person, health and environment. The revised model also clarifies the components of symptom management strategies to include specific questions such as: ask, who, what, how, when, to whom, where, how much, and why a strategy is implemented [5]. Both the original model and the updated model highlighted the importance of all of the central concepts ongoing interaction with each other.

### *Meaning and Logical Adequacy*

SMT has three major concepts: symptom experience, symptom management and symptom outcomes [2]. The authors managed to define the key concepts clearly as well as describe their relationship with the dimensions of nursing science. The multidirectional arrows portray the associational relationships among the three components of symptom management. Projected associations are designated merely for the direct and indirect health and illness aspects. The SMT is a middle range theory limited to the phenomenon of symptom management, but is comprehensive in its application for various illnesses, developmental groups and populations [5].

Some of the limitations of the logical adequacy of the SMT include the difficulty with predicting the directional relationship. Secondly, this theory may lack the ability to be evaluated across illness trajectory. Lastly, the SMT may be limited in differentiating between acute and chronic symptoms.

### *Usefulness*

Theory is relevant across various populations that experience symptoms or are at risk for experiencing symptoms due to the disease process. The SMT has been established as a useful framework for research in adults and pediatric patients with a variety of illnesses states [6]. The SMT also been used to explore differences based on race and ethnicity and caregiver symptoms. This model can be applied when examining a single symptom and multi-symptoms with inclusion of variables such as financial cost, health and employment related costs, costs of poorly managed symptoms, and other costs associated with symptoms management.

### *Generalizability*

Applicable across settings and supports the development of individual or group intervention strategies. This model is flexible to be able to examine and handle multiple symptoms at once. Some research has shown that the SMT could be applied to not only

a single symptom, but to multiple symptoms as well. The theory is broad enough that it can cover both of these situations. Symptoms in chronic illness can either be simple and singular, or they can come in clusters, often caused by each other or treatment. Current research exists which supports the application of symptom management to symptom clusters [7,8]. The SMT, however, is restricted to the process of symptom management and the framework in which occurs.

### *Parsimony*

The SMT has clearly defined three components and also includes the three dimensions of nursing science. The multidimensional relationship between the concepts presented in the visual representation model matches the verbal description of the model. The model is complex and includes numerous variables that could be considered within dimensions and interrelationships within each component.

### *Testability*

As outlined by Humphreys [3], support for the testability of the SMT is its foundation in the empirical work of its authors. The model has been tested among a wide variety of illnesses. However, the scope and complexity of SMT limit the number of proposed relationships that can be investigated in a single study.

## **Comparing of the SMT with the Theory of Unpleasant Symptoms**

### *Origins*

The Theory of Unpleasant Symptoms, (TOUS) like the SMT, originated at the UCSF. This theory was created by a student of graduate studies, whereas the SMT was created by UCSF faculty. The TOUS theory was generated during analysis of a single concept to multiple concepts [9]. In contrast, the SMT model was based on collaborative research of faculty members of the Symptom Management Faculty Group in UCSF.

### *Meaning and Logical Adequacy*

In the TOUS a symptom can occur alone or lead to another symptom or even multiple symptoms. The TOUS also includes an application of feedback loops and symptom experience concept with all the components communicating with each other at the same time.

Whereas in the SMT symptoms are connected via directional link between the components of symptom experience and the components of symptom management strategies that may be later utilized to manage symptom outcomes. Each of the theories described their concept relationship in a logical manner. The SMT is more comprehensive due to its inclusion of financial, health and employment related costs as well as other costs associated with the patient's life [5]. The TOUS does not include either concept of costs related to symptoms or any symptoms management strategies. More importantly, the SMT includes three domains of the nursing paradigm, whereas the TOUS does not.

### *Usefulness*

The TOUS takes into account the symptoms and the symptoms feedback and includes concepts such as physiological factors and situational factors. The SMT could be utilized for investigation of the self-care strategies used by patients and the relationship between these strategies and the components of symptom experience. The SMT also could be used to examine symptoms or symptoms cluster with variables such as cost impact and management strategies.

### *Generalizability*

Both the TOUS and the SMT have been used in a variety of nursing research within different patient populations. The TOUS does not discuss the potential costs related to symptoms or any symptoms management strategies, whereas The SMT is limited to the process of symptom management and the context in which occurs.

### *Parsimony*

The concept and relations among both theories are described clearly regardless of their broad content. Both theories also provided visual representation of the concepts and their relationships. The visual representation that was provided for both models reflects verbal descriptions of the models presented by the authors of both theories.

### *Testability*

When necessary the researcher should be able to draw a hypothesis from both theories. Concepts and relationship of the TOUS as well as the SMT have been

empirically tested and the relationship they proposed is generally accepted.

## Comparison of the SMT with the Symptom Interpretation Model

### *Origins*

The Symptom Interpretation Model (SIM) is based on Leventhal's Common-sense Model of Self-Regulation. Leventhal, a scientist, generated the SIM from psychological literature [10]. The SMT was created by the faculty of the University of California in San Francisco (UCSF) School of Nursing.

### *Meaning and Logical Adequacy*

The SIM and the SMT includes three major concepts. The major concepts of the SIM include: input, interpretation, and outcome and the SMT model includes: symptom experience, symptom management and symptom outcomes. The SIM takes into consideration the individual interpretation of the symptoms [10], whereas the SMT embraces the individual's perception, evaluation, and response to a symptom and symptom clusters as well as symptom management strategies [2,3]. The SIM differs from the SMT in that the SIM does not have a clear description of how the three concepts are connected.

### *Usefulness*

The SIM, due to its inclusion of interpersonal viewpoint and cognitive evaluation, could be utilized to assess symptoms perception of patient who are cognitively intact [10]. The SMI also could not be utilized in patient population where cognition is potentially impaired. The SMT, due to its comprehensive design, could be applied to a variety of populations and assessment of not only an individual symptom, but also symptom clusters.

### *Generalizability*

The SIM is limited to interpretation of symptoms in patients who are cognitively intact. The SMT is restricted by the framework in which it takes place and to the assessment of symptom management.

### *Parsimony*

Parsimony of the SIM is not clear as the theory's concepts depend on many dynamic variables which interact with each other independently to allow the researcher to understand symptom experience [10]. All the concepts required multiple steps of cognitive appraisal and the process of symptom assessment is unclear. The parsimony of the SMT is clear and components as well as relationships are described succinctly with the addition of vibrant visual interpretation of all components. Teel and colleague [10], did not provide visual interpretation of the SIM concepts.

### *Testability*

The SIM concepts can be tested by allowing the researchers to generate needed hypothesis. Just as Cook and colleague [11], utilized the SIM to provide a framework for their research in understanding patients' symptom experiences and their patterns in patients with HIV. The SMT has been used by many researchers as their framework. One of the recently published articles by Newland et al. applied the SMT to investigate the relationship among a set of symptoms.

## Material and Methods

### *Search Strategy*

An electronic search of several computerized databases was conducted including: PubMed, Web of Science, Embase, CINAHL and Google Scholar. The author utilized the following MESH terms: "Symptom Management Model" AND "neurological disorders" AND "neurological diseases" (Figure). The search was limited to human subjects and the English language. The search was not limited by publication year as the SMT is relatively new. The following inclusion criteria was followed when reviewing the abstracts: peer-reviewed reports of original research; articles published in the English language; articles included the use of SMT as study framework. Studies were excluded if they were: abstracts, editorial, commentaries, not-related to the topic, or if application of SMT was not used as a study framework. This search yielded a total of 87 articles. After removing duplicate articles and those not related to the topic. A total of 19 abstracts were reviewed for inclusion of SMT as part of research conceptual framework. The search then yielded a total of six articles for review. One additional article was found via a review of secondary citation of article found in prior search for total of seven articles.

Section/topic	#	Checklist item	Reported on page #
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	Page 1
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	Page 1
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	Page 3
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	Page 4
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	NA
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	Page 13
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	Page 12
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Page 12
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	Page 12
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	Page 12
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	Table 1
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	Table 1
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	Page 17
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I <sup>2</sup> ) for each meta-analysis.	Page 17
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	Page 18
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	NA
<b>RESULTS</b>			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	Figure 1
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Table 1
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	NA
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Table 1
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	NA

Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	Page 12
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	NA
<b>DISCUSSION</b>			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	Table 1
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	Page 19
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	Page 19
<b>FUNDING</b>			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	Page 13–17

Figure. PRISMA 2009 Checklist — Analysis of UCSF Symptom Management Theory and Theory Implication for Persons with Neurological Disorders/Diseases [From: Moher D., Liberati A., Tetzlaff J., Altman D.G., The PRISMA Group, Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med.* 2009;6(7): e1000097. doi: 10.1371/journal.pmed1000097].

### Study Quality

Study quality was assessed using the Quality Index (QI) checklist developed by Downs & Black. The QI checklist is commonly used to assess the methodological quality of systematic reviews, randomized clinical trials (RCTs) and non-randomized studies. Two researchers (KCL and BP) independently evaluated the studies using the Downs & Black QI checklist [12]. Differences in scores were rechecked and consensus achieved by discussion. Two articles were not assessed by utilizing QI as they were literature reviews not a systematic review. Researchers utilized the two articles as the current research is very limited in discussing SMT implication for persons with neurological disorders [13,14].

### Results

A total of seven articles (Table) was included to support empirical relationships between SMT components evidenced in studies involving adults with neurological disorders/diseases. Overall, the literature supports SMT as a theoretical framework for symptoms management for persons with neurological disorders/diseases. Several studies utilized the SMT as a theory applicable to multiple symptoms or symptom clusters. These studies included implications of the theory principle of symptom or cluster of symptoms. This was accomplished on the premise that symptoms, or clusters of symptoms, are required to be considered based on all three components of the theory and that, only then, symptom management can be effective [5].

One of the oldest articles found was written by Wallhagen and Brod [15]. In their studies, one of the aims was to evaluate the impact of the patient's perceived control over symptoms of Parkinson disease (PD). Parkinson disease (PD) is a chronic and progressive neurological movement disorder also classified by WHO (2006) as one of the neuropsychiatric disorders. Currently there is no cure for PD and treatment options aim towards symptom management of symptom cluster to help person maintain a satisfactory quality of life [15,16]. Wallhagen utilized conceptual framework of the SMT to suggest that the perceived control of symptoms experience may be important to the patient and the family's outcome. This cross-sectional study finding supported the importance of symptom management not only from a patient perspective, but also from a care giver perspective. Study recommendation was to manage patient symptoms by developing the skills that would allow patients to perceive control over their symptom or symptoms [15].

Backer [17], utilized the SMT multidimensional analysis to also study the symptoms experience of patients with PD. Backer [17], however, suggests that the SMT has some degree of flexibility in examining symptom clusters. Backer's study design utilized descriptive correlational analysis, and this study aims to examine the extent of distress related to 13 symptoms of PD. The study examined the relationship among the symptoms experienced, including variables such as symptom presence, intensity, duration and frequency of symptoms occurrence. The author found that distressing symptom experience was described by patients while facing freezing gait, trouble concentrating, postural instability and sleep disturbance. Symptom status

Table. Summary of UCSF Symptom Management Theory studies among persons with Neurological Disorders/Diseases

Author/ Year/ Location	Participant Details	N	Theoretical Framework	Measures of Symptom Management	Results	Quality Index*
Cross Sectional						
Newland, Fearing, Riley & Neath (2012) USA	Multiple Sclerosis Patients mean age=43 yrs. male n=0 female n=40	40	SMT	Brief Pain Inventory Long Form (BPI-LF), McGill Pain Questionnaire, Lee Fatigue Scale, Beck Depression Inventory, General Sleep Disturbance Scale, PASAT, Demographic Data/Health/Medication History	One symptom cluster of pain, fatigue, depression, sleep disturbance and impaired cognitive function. Results demonstrated a relationship between that symptom cluster and employment status. (p<0.05)	27
Motl, Suh, & Weikert (2010) USA	Multiple Sclerosis Patients mean age=51 yrs. male n=29 female n=104	133	SMT and TOUS	Fatigue Severity Scale (FSS). The Center for Epidemiological Studies-Depression (CES-D), McGill Pain Questionnaire (SF-MPQ). Perceived Deficit Questionnaire (PDQ), The 29-item Multiple Sclerosis Impact Scale (MSIS-29).	Significant and Moderate negative correlations between overall symptoms and physical activity. There was significant and small negative correlation between fatigue and physical activity. No significant correlations of physical activity with pain and depression. (p <0.05)	30
Wallhagen & Brod (1997) USA	Parkinson Disease Patients age=60 yrs. or older gender=NR	101	SMT	One hour initial Patient interview and one year later 20 minute phone interview. Interviewer assessed control beliefs and well-being. Well-being was assessed by Medical Outcomes Study Mental Health Index (MOS). Spouse questionnaires were mailed at the time of the follow- up, and included the MOS and the Caregiver Burden Interview (CBI).	PPC over symptoms associated with patient well-being = (r=.22, p=0.26), PPC over symptoms associated with better caregiver well-being after controlling for disease severity = (p=0.29), PPC over disease progression and patient well-being = (r=.02, p=0.92), PPC over disease progression and caregiver burden = (r=-.07, p=0.66)	20
Descriptive Correlational						
Backer (2006) USA	Parkinson Disease Patients mean age=66 yrs. male n=54 female n=31	85	SMT and TOUS	Symptom Experience Questionnaire	The mean number of symptoms reported was 7. The most distressing symptom was off time (SD=0.81), followed by freezing gait (SD=1.1), postural instability (SD=0.88), sleep disturbance (SD=0.97, and difficulty concentrating (SD=0.9).	22
Qualitative						
Newland, Thomas, Riley, Flick & Fearing (2012) USA	Multiple Sclerosis Patients mean age=42 yrs. male n=4 female n=12	16	SMT	Questions generated by the investigator and open ended probes to gather more information.	Fatigue was commonly mentioned and other terms such as “drained”, “wiped out” and “shut down”. Cognitive symptoms including memory disruptions as well as fatigue with cognitive loss was also found during this study.	25
Literature Review						
Crayton, Heyman & Rossman (2004) USA	Multiple Sclerosis Patients mean age=NR gender=NR	NR	SMT	Review of effective approach to managing the symptoms of Multiple Sclerosis.	Review concluded that multimodal approach is necessary to managed symptoms of Multiple Sclerosis successfully.	Not graded
Johnson (2008) USA	Multiple Sclerosis Patients mean age=NR gender=NR	NR	SMT	Review of fatigue symptom and its impact on patient quality of life of patient with Multiple Sclerosis.	Review concluded that fatigue is common in patient with Multiple Sclerosis and that it has significant impact on a patient's quality of life.	Not graded

\* based on Downs S.H., Black N., *J Epidemiol Community Health*. 1998;52(6):377–384; SMT=Symptom Management Theory, TOUS=Theory of Unpleasant Symptoms, PPC=Patient Perceived Control, NR=not reported.



outcomes were impacted by symptoms distress that could potentially make the symptoms worse. Due to the above finding, the author suggested that symptoms management should be based on numerous symptoms assessments including asking patients about symptoms duration, intensity and frequency.

Other studies involving patients with neurological neuropsychiatric disorders have provided support for the SMT's proposed relationships between the symptom experience and outcome. Crayton and colleague [14], provided a literature review suggesting that multimodal components of the SMT provide optimal results when managing the symptoms of a patient with Multiple Sclerosis (MS). Multiple Sclerosis, like PD, is a chronic and progressive neurological movement disorder also classified by WHO as one of the neuropsychiatric disorders. MS is defined as an autoimmune disease that affects the patient's central nervous system. MS and PD, currently do not have a cure. Therefore treatment objectives are towards multi-system symptom management occurring either in clusters or independently from each other [1,18]. Crayton and colleague [14] summarized that symptom management is crucial to MS patient quality of life especially due to lack of cure. Author suggests that for symptoms outcome to be effective, care providers should utilize effective communication and patient education. In addition, a combination of physical and occupational therapy and pharmacological intervention should be utilized in order to achieve ultimate symptom management and to avoid symptom recurrence.

Johnson [13], applied the SMT to study framework to guide health care providers in the assessment and treatment of one of the most common symptoms of MS, fatigue. The study suggests that the SIM can be used to examine combinations of related symptoms concurrently while examining fatigue. This is especially important for patients with MS as fatigue usually appears with other symptoms such as cognitive symptoms, depression and others. Author advises that fatigue and related symptoms assessment should be conducted frequently and guide symptom outcome and symptoms management.

The SMT was also applied by Motl et al. [19], in their research which studied definite symptoms as links of physical activity of persons with MS. Questionnaires distributed to study participants measured not only overall symptoms experience, but also symptoms such as depression, fatigue, ambulation, physical activity and pain. The study finding correlated that not only total symptoms experience, but also individual symptoms experience influences the participant dormancy. Furthermore, correlation analysis proved that the intensity of overall symptoms has a substantial effect on the physical activity of the participants. Motl and colleague

[19] finding has major impact on symptom management of patients with MS, as physical activity is often utilized as one of the interventions to manage the disease symptoms. The authors established that effective symptoms management via either physical activity or pharmacological intervention is imperative. Such intervention should be encouraged to avoid symptoms occurrence and are essential in actual symptoms management.

Humphreys and colleague, describes the concept of symptom clusters, distinguishing that often a number of symptoms occur together, and that the symptom experience is individual for each patient. This also could easily be applied to patients with MS. Motl and colleague [20], noticed the opportunity to examine a particular MS symptoms cluster and its association with patient quality of life (QOL) based on the essential components of SMT. MS symptoms of cognitive complaints, depression, pain and fatigue were examined as a cluster. Collected findings demonstrated that empirical evidence exists that support hypothesis of symptoms cluster and its significant association with QOL outcomes in patients with MS.

Other study written by also applied SMT framework to the concept of MS symptom clusters. This time sleep disturbance was added to the cluster of depression, cognitive function and fatigue. Symptom cluster was compared with pain severity and demographic variables. Results supported the correlation of the symptom clusters with MS patient employment status, as well as correlation of pain, as being the factor of increasing severity of inspected symptom cluster. Author's finding summarized that symptoms management should be preemptive and ongoing. The patient should be educated and encouraged to control pain and to utilize techniques to reduce stress to avoid unemployment.

The last study purpose was to define and recognize co-occurrence symptoms by using quantitative approach [11]. Three focus groups conducted an examination of symptoms such as balance, heat intolerance, vision and cognition. The study finding documented that many of co-occurring symptoms may not be noticeable to others but are inconvenient to the person experiencing them. Symptom management should be geared toward identification of not only individual symptom but also co-occurring symptoms as well. Any lapse in symptoms management should be evaluated frequently and the patient should be encouraged to describe the symptoms and the internal correlation of symptoms. Then appropriate intervention and resources can be recommended and positive symptom outcome met.

## Discussion

This systematic review provides important evaluation of current evidence of SMT utilization as a framework to analyze the theory implication for persons with neurological disorders/diseases. Limited literature currently exists supporting the application of the SMT and the possible guidance of symptom management of persons with neurological disorders/diseases. Studies found during this search only included Parkinson disease and Multiple Sclerosis as examples of neurological disorders/diseases. They are limited to only examining a few aspects of complex neurological disorders symptoms which often appear in clusters as well as individually. Existing studies did, however, provide empirical support of the associations between theory components apparent in presented studies.

The SMT has been used in research that focused on symptom clusters. Author found several articles describing cluster symptoms in patients with neurological disorders/diseases.

Studies by looked at symptom clusters in adult patients with neurological disorders/diseases. The advantage of looking at symptom clusters is that if we improve one symptom, other symptoms in the cluster may be relieved. The SMT is applicable to symptom management theory in that we are looking at a cluster of symptoms but each cluster has individual symptoms.

The SMT also proposes a directional link between the components of symptom experience. These components include symptom perception, evaluation, and response as well as symptom management strategies including self-care strategies used to manage symptoms. The Baggott and colleague (2010), study used the SMT to report and evaluate patient symptoms that were the most frequently experienced by patients with PD. The study found that the symptoms which were more frequently experienced were not the ones to cause the most distress to the patient. Walhagen and Brod [15], examined the PD patient symptom perception of symptom control as well as patient perceived control over disease progression. In this study the SMT provided empirical support that self-care strategies should be used for patients and that the relationship between these strategies and the components of symptom experience is existing.

The SMT as a theory uses symptoms as the major component and discusses how individuals may respond to their symptoms. The SMT also describes influencing factors in the interpretation of symptoms. This aspect of the theory was explored by both Johnson [13] and Motl and colleague [19]. Johnson [13], supported that the SMT should be utilized as a guide to assess and treat the symptom of fatigue in patients with MS. Fatigue was described as a subjective symptom that management

of that symptom would be highly individualized. Motl and colleague [19] also correlated fatigue as an influencing symptom which determines lack of physical activity in patients with MS. Both observations are consistent with the concepts of the SMT that describe the symptom experience based on how the symptom is experienced and handled by the individual person.

NND such as PD and MS cause a substantial burden on global health due to their progressive and debilitating disease process. They currently lack a cure as well. Due to the fact stated above, studies are also deficient in examining the association among the symptoms with application of longitudinal design. Other limitations of studies examining symptoms of patients with PD include small sample size. This can limit the true representation of PD population and symptoms management. More studies are needed to examine individual components of symptom experience in neurological neuropsychiatric disorders. Diseases such as Alzheimer and Epilepsy are also progressive and debilitating. The SMT should be used to observe the symptom experience, symptom management, and symptom outcomes occurring in these neurological diseases [2].

## Conclusions

Patients with neurological disorders/diseases often experience a vast variety of symptoms occurring either independently or in clusters. With significant variability within neurological disorders/diseases approaches to symptom cluster and individual symptom perception, research is deemed essential. Walker and Avant's [4] analysis of the Symptom Management Theory that the theory is parsimonious, logical in its adequacy and may be generalized to other studies. This systematic review of vital existing studies created a solid beginning to explore recommendations to promote standards for symptom management in future investigations of neurological disorders/diseases. This is especially important in neurological disorders/diseases as the majority of the above mentioned NND are progressive, currently have no cure and treatment options are based on symptoms management.

## Implications for Nursing Practice

The SIM model selected to use as the framework to analyze implication of the theory for persons with neurological disorders/diseases was appropriate, and has been utilized in several studies. The SIM is flexible to allow researchers to examine and compare multiple symptoms at once as well as individually. This aspect of the theory is especially important when reviewing

symptoms management of patients with neurological diseases. This is due to its complexity and individual patient experience of different symptoms. Further research to examine symptom outcomes as a factor is also essential and should include patient self-care ability, financial status, morbidity, comorbidity, mortality, quality of life, resources utilization, emotional status, and functional status. Research of symptom outcome in patients in neurological disorders is essential as they are the source of substantial burden on global health.

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### Corresponding Author:

Klaudia Cwiekala-Lewis  
The University of Phoenix,  
College of Health Sciences and Nursing  
4035 S. Riverpoint Pkwy, Phoenix, AZ 85040, USA  
e-mail: [klaudia27@email.phoenix.edu](mailto:klaudia27@email.phoenix.edu)

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