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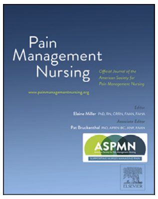

Review Article

# Deconstructing Pain Disability through Concept Analysis

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## ABSTRACT

*Objective:* Pain disability is a complex and challenging problem that impacts the daily lives of individuals living with persistent pain. Although this concept is measured throughout pain populations, conceptual clarity is needed to identify the defining characteristics and further understand what comprises this experience for clinical translation.
*Design:* We completed a concept analysis to identify major attributes and provide a broad framework of pain disability for improved recognition throughout the discipline of nursing.
*Data Sources:* Literature searches in PubMed, CINAHL, PsychINFO, and Scopus identified 39 relevant cross-disciplinary articles published between January 1990 and November 2017.
*Review/Analysis Methods:* We implemented Avant and Walker's method of concept analysis to establish the attributes, antecedents, and consequences of pain disability.
*Results:* Two major attributes of pain disability are discussed, including (1) physical and/or psychological responses leading to a functional loss; and (2) the degree of ability to fulfill role expectations. The antecedent to the development of pain disability is a painful trigger. Three leading consequences are identified as suffering, pain reactivity, and secondary loss.
*Conclusions:* Pain disability is a fluid concept that is characterized by the subjective experiences of the individual. A new conceptualization of pain disability is offered as the inability to maintain role expectations due to the result of a painful trigger and subsequent physical and/or psychosocial dysfunction.

Pain disability (PD) presents a complex and challenging problem for individuals who experience persistent, or chronic, pain. Persistent pain is a leading cause of worldwide disability and a major contributor to high medical costs as well as lost work productivity (GBD 2016 Disease and Injury Incidence and Prevalence Collaborators, 2016). In the United States, the cost of lost work productivity as a result of disabling pain was estimated to be between $297.4 to $335.5 billion in 2010 (Gaskin & Richard, 2011). The National Institute of Nursing Research has identified pain research as a top priority with a focus on identifying biobehavioral mechanisms, developing and implementing targeted therapies, and improving treatment-related concerns (National Institutes of Health, n.d.). In addition to a national focus on pain research, The Joint Commission (2018) recently released updated recommendations for assessment of pain in hospitals, which emphasize evaluating the physical limitations of patients experiencing pain. Although the evaluation of PD has been previously recommended as a standard assessment in pediatric and adult patients with chronic pain, its inclusion as a component of the nursing assessment is limited (Bernier, Strobel, & Lucas, 2018; Dworkin et al., 2005; McGrath et al., 2008).

The concept of disability is defined by the World Health Organization (WHO, 2011) as “the negative aspects of the interaction between individuals with a health condition…and personal and environmental factors” (p. 7). The Americans with Disabilities Act (ADA) further elucidates this definition, describing disability as “a physical or mental impairment” which limits one's ability to participate in daily activities (U.S. Department of Justice, 2009). Evaluating pain as a disability is essential for understanding how persistent pain affects daily life (Fillingim, 2017; Tabor, Keough, & Eccleston, 2017). Numerous scales are available to measure the concept of PD in populations with both acute and chronic pain (Grotle, Brox, & Vøllestad, 2005; Smeets, Koke, Lin, Ferreira, &

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Demoulin, 2011). Although *pain disability* is a widely accepted term, other terms are also used across these instruments including *pain-related disability, disabling pain, functional disability,* and *pain-associated disability syndrome* (Blyth, VanDer Windt, & Croft, 2015; Bursch, Walco, & Zeltzer, 1998; Sullivan, Sullivan, & Adams, 2002; Walker & Greene, 1991). For clarity, the term *pain disability* will be used herein as an inclusive term of all related terms as listed earlier.

Although diversity in measures can help to understand different concepts, diversity in terms has led to substantial inconsistency and lack of clarity in prior work. For example, the relationship between pain sensitivity, which is often defined as the physical and emotional responses to noxious or perceived noxious stimuli, and PD are often inconsistent (International Association for the Study of Pain [IASP], 2017; Ravn, Frederiksen, Skovsen, Christrup, & Werner, 2012). A meta-analysis by Hübscher et al. (2013) examined the relationship between Quantitative Sensory Testing as a measure of pain sensitivity and low back pain disability across 40 studies. The results of this analysis found a weak correlation between measured pain sensitivity and self-reported measures of disability, although measures of disability varied across the sample and psychosocial cofactors were not considered. These results lead us to infer that perceived pain severity does not equate to PD.

Others have also found a limited relationship between pain severity and disability (Nahin, 2015; Rabey, Slater, O'Sullivan, Beales, & Smith, 2015; Von Korff, Dworkin, & Le Resche, 1990). Bagraith, Strong, and Sussex (2012) point out that many of the pain disability measures concentrate on the concepts of interference and impairment as a direct result of nociceptive input. It is possible that these measures do not encapsulate the entire experience of PD—for example, the emotional aspects—therefore leading to the lack of conceptual understanding.

Conceptual clarity is a vital aspect of measurement and the ability to develop precise clinical evaluation criteria. Considering the impact of chronic pain at individual and systemic levels, prioritizing the understanding of PD for clinical translation is essential. This is particularly important for the discipline of nursing because nurses are often clinical gatekeepers who may be the first to recognize signs of PD. Additionally, increased recognition supports the development of interventions to prevent or reduce the consequences of PD and improve the daily lives of those enduring this experience. To advance discipline-wide recognition of PD, this concept analysis aims to deconstruct this concept and to provide a broad framework for nurses to identify the essential characteristics of individuals who may be vulnerable to or are suffering from this experience.

## Methods

The method established by Walker and Avant (2011) guides this concept analysis. A concept analysis is an evaluative process that supports theory construction through characteristic, or attribute, identification of a specified phenomenon (Walker & Avant, 2011). After identifying the concept of interest and the aim of the analysis, this structured method follows six essential steps, including: (1) thoroughly identifying all uses of PD; (2) establishing the attributes; (3) identifying a model case that represents pain disability by displaying all attributes; (4) presenting a borderline case; (5) defining the antecedents and consequences of PD; and (6) determining the empirical referents that directly reflect the phenomenon of PD (Walker & Avant, 2011).

A cross-disciplinary literature search was performed between August and November 2017. Databases searched included PubMed, CINAHL, PsycINFO, and Scopus. Key terms used included (1) "pain disability"; (2) "pain AND disability"; (3) "disabling pain"; and (4) "pain-related disability." All searches were limited by the publication date of 1990 to mirror the year the Americans with Disabilities Act was signed into law, thereby providing a clear starting point for the national and occupational use of the term *disability* for this analysis (Americans with Disabilities Act National Network, n.d.). It should be noted that the term *pain disability* was used before 1990, so the starting date for the literature search is not intended to suggest an origin date for the creation of PD as a concept.

Articles that met inclusion criteria were peer-reviewed articles in English that defined PD, disabling pain, or pain-related disability; provided identifiable antecedents or attributes; and/or detailed the theoretical or conceptual development or application of a clinical instrument measuring PD. Articles were excluded if they did not directly discuss the concept of PD, focused solely on administration of tools or questionnaires relating to the concept, or focused on individuals with an intellectual or developmental disability in pain. Figure 1 displays the flow diagram of the literature search.

Following the method of Walker and Avant (2011), no theoretical model was implemented while identifying relevant resources. However, the biopsychosocial model guided identification of individual factors affected by the PD experience. The biopsychosocial model is a widely accepted framework for identifying and interpreting biological, psychological and social factors that contribute to the perception and experience of pain (Engel, 1977; Gatchel, Peng, Peters, Fuchs, & Turk, 2007). This model posits that incorporating these three factors allow for the appreciation that a disease state transcends biological findings and includes the individual experience of the condition (Engel, 1977). Because nurses directly manage patients living with persistent pain, this framework provides a holistic approach to understanding the mutliple factors that contribute to a painful and disabling experience as well as how these factors interact with each other.

## Results

A total of 6,608 articles were identified in the primary searches. Of those, 112 were assessed for eligibility and 39 were included in the final concept analysis. Disciplines found to use the concept included medicine, rehabilitation sciences, nursing, ethics, social work, psychology, epidemiology, human science and biology, and theoretical philosophy. The articles originated from the United States (n = 23), Australia (n = 5), Canada (n = 3), the Netherlands (n = 3), the United Kingdom (n = 2), Finland (n = 1), Norway (n = 1), and Hong Kong (n = 1). The findings of this concept analysis are summarized in Figure 2, which presents a model of PD.

### *Uses of the Term Pain Disability*

In contrast to operationalizing the terms *pain* and *disability* independently, the term *pain disability* is narrowly concentrated in the clinical literature, with a focus on individuals experiencing pain. Circa 1990, the use of the concept centered on vocational status and the ability for individuals with chronic pain to return to work (Aronoff, 1991; Goldman & O'Neill, 1990; Jerome & Gross, 1991; Tait, Chibnall, & Krause, 1990). In 1991, Aronoff candidly specified that *disability* was a legal term, whereas *impairment* was a medical term and, further, that they were not to be substituted for one another. As the understanding of PD has evolved over the last 25 years, the solitary term *disability* has acquired a more causal nuance, implying an experiential state that interacts with a local environment (WHO, 2011). This is reflected in more recent clinical literature, such as the description of PD as both "a biological reality and a social construction" (Stahl, 2016, p. 1).

The PD concept is used both as an outcome of pain as well as a mediator of disease burden (Blyth et al., 2015; Lee et al., 2015). Prior

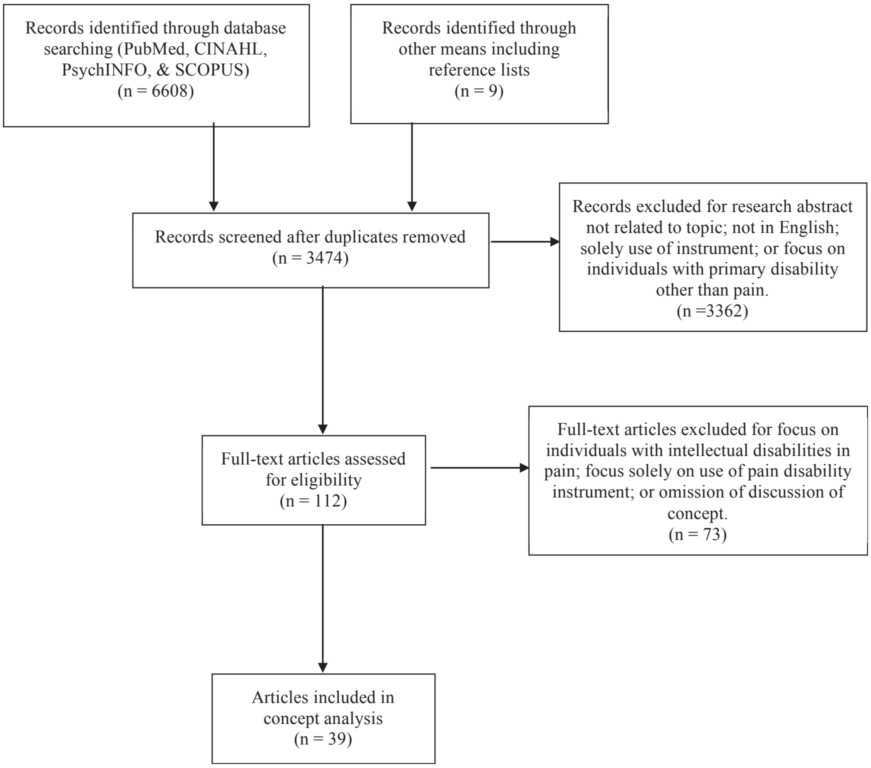

**Figure 1.** Flow diagram of literature search used for concept analysis.

work has consistently referred to the *functional* impact of pain as an indicator of PD, with an emphasis on the ability of individuals experiencing pain to interact with their environments. Numerous measures of PD are available to evaluate functional status and interference of pain that are most representative for specific populations with pain (Grotle et al., 2005; Tait et al., 1990; Tucker et al., 2014). The consistent theme identified through the uses of the term thus far reflects a working definition that PD is an indicator of the functional capacity for individuals to interact with their environment in the context of managing a painful experience.

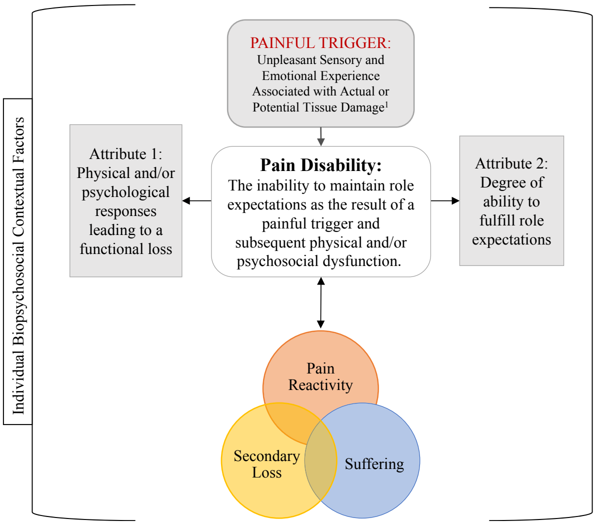

**Figure 2.** A model of pain disability.
(From International Association for the Study of Pain, 2017.)

## *Defining Attributes*

From the literature reviewed, we identified two defining attributes that aid in recognition of PD: (1) the physical and/or psychological response to a painful trigger leading to a functional loss; and (2) the degree of ability to fulfill role expectations. These characteristics highlight the critical importance of the person-environment interaction as opposed to focusing solely on the inability to complete a task (Bagraith et al., 2012; WHO, 2011). PD is understood as a multifactorial phenomenon that closely interacts with many individual factors; therefore it is important to emphasize that all experiences of the concept are deeply personalized (Saariaho, Saariaho, Karila, & Joukamaa, 2012; Tait et al., 1990; Turk, 1996). To recognize and integrate these biopsychosocial characteristics, contextual factors that contribute to the PD experience are also outlined. Contextual factors are not considered defining attributes because they are not critical to a differential diagnosis of PD but rather assist in understanding the severity of the disability for the individual and may help to guide interventions.

### *Physical and/or Psychological Response to a Painful Trigger Leading to Functional Loss*

The functional loss resulting from a physical and/or psychological response to a painful trigger is a primary attribute of PD. The U.S. Code of Federal Regulations (CFR) defines functional loss (U.S. Department of Veterans Affairs, 2017) as “the inability…to perform the normal working movements of the body with normal excursion, strength, speed, coordination and endurance.” Although in the CFR this definition specifically pertains to the musculoskeletal system, it remains applicable to this concept analysis in the broader understanding of PD.

The physical responses to a painful trigger may involve a restriction in physical capabilities such as being able to pick an item off the floor, walk up or down stairs, or perform range of motion

(Horgas, Yoon, Nichols, & Marsiske, 2008; Moseley, 1999; Tucker et al., 2014). This may be characterized by a restriction in movement or a loss of mobility and/or strength (Goldman & O'Neill, 1990; U.S. Department of Veterans Affairs, 2017; Scudds & Østbye, 2001; Vlaeyen, Kole-Snijders, Rotteveel, Ruesink, & Heuts, 1995). Additionally, the capacity to perform functional activities may gradually decrease throughout the day, leading to a compromised state (Bianchini, Greve, & Glynn, 2005; Simmonds, Kumar, & Lechelt, 1996). Physical responses in the form of proactive effort taken to diminish pain should also be considered, such as laying down or guarding the painful site (Prkachin, Schultz, & Hughes, 2007; Sorbi et al., 2006).

A multitude of psychological responses to a painful trigger may be present in the face of PD associated with both emotional and cognitive factors (Bianchini et al., 2005). These behavioral manifestations range from avoidance behavior to maladaptive appraisals (Turk, 1996). The connection between psychological responses and functional loss incorporates a paralyzing effect in which the individual has made a conscious or subconscious decision to not engage in a functional activity. Such characterizations often include fear of movement (i.e., kinesiophobia) or (re)injury and associated avoidance behaviors (i.e., agliophobia) (Severeijns, Vlaeyen, van den Hout, & Weber, 2001; Sorbi et al., 2006; Vlaeyen et al., 1995; Zale, Lange, Fields, & Ditre, 2013). The concept of catastrophizing is also consistently cited in the literature (Arnow et al., 2006; Knussen & McParland, 2009; Lee et al., 2015; Proctor, Gatchel, & Robinson, 2000; Severeijns et al., 2001; Sorbi et al., 2006; Sullivan et al., 2002; Vlaeyen et al., 1995). Pain catastrophizing can be identified by the traits of rumination, magnification, and helplessness (Sullivan, Bishop, & Pivik, 1995). Lastly, anxiety and depressive preoccupation may contribute further to functional loss as an individual appraises their inability to maintain obligatory and voluntary activities (Scudds & Østbye, 2001; Tait et al., 1990; Turp, Kowalski, & Stohler, 1997).

### *Degree of Ability to Fulfill Role Expectations*

In this concept analysis, role expectations are broken into two major dimensions: social and occupational. The use of the term *expectations* is fluid and defined by the local environment and culture of the individual in pain (Stahl, 2016). The use of the term *degree* indicates that the level of PD reflects the extent to which individuals are unable to interact with their environment and fulfill their role. Withdrawal from role expectations is most often secondary to the first attribute, physical and psychological consequences of persistent pain. This seemingly linear process readily becomes cyclical because disability may lead to increased pain (Bursch et al., 1998).

Social role expectations vary from participation in familial and interpersonal relationships to engagement with community activities. Individuals with PD may retreat from partaking in leisure activities or have increased difficulty maintaining relationships with others, leading to social isolation (Etherton, 2014; Horgas et al., 2008; Saariaho et al., 2012). Examples of such instances include the inability to complete daily household chores, reduced capacity to play with a grandchild, or cancelling participation in a local sports club.

The inability to fulfill occupational role expectations tends to have greater association with PD, particularly in relation to seeking financial benefits. As part of the second attribute, this role dimension is associated with inability to keep up with job demands or avoidance of work activities related to a fear of reinjury (Aronoff, 1991; Coggon et al., 2013; Vlaeyen et al., 1995). Conversely, the individual may desire to return to work, but the employer does not provide accommodations for a modified work load and further inhibits the worker's ability to meet role expectations (Teasell & Bombardier, 2001). For children and adolescents, inability to fulfill occupational role expectations includes the incapacity to consistently attend school or meet educational requirements for advancement and difficulty maintaining participation in daily activities (Vetter, Bridgewater, Ascherman, Madan-Swain, & McGwin, 2014). Further, this attribute may also prevent involvement in other developmentally appropriate activities, including sports and social engagement. Over time, separation from these activities can make it more difficult for the individual with pain to reengage and further compounds the negative physical or psychological responses, leading to additional functional loss for the individual.

### *Contextual Factors*

Contextual factors are potential vulnerabilities that an individual may carry into the PD experience. These factors parallel the biopsychosocial model and include biological, psychological, and social components (Gatchel et al., 2007). Although these categories closely relate to the defining attributes, they vary by individual and detail the complexities of PD as a phenomenon.

Biological contextual factors include age, sex, race, and genetic predisposition (Arnstein, 1997; Aronoff, 1991; Blyth et al., 2015; Gatchel et al., 2007; Horgas et al., 2008; Tait et al., 1990). History and treatment of chronic illness may also contribute (Gatchel et al., 2007; Scudds & Østbye, 2001).

Psychological factors encompass an array of behavioral characteristics, including history of psychological distress, depression, and pain-related fear (Arnow et al., 2006, 2009; Blyth et al., 2015; Florence & Asken, 1994; Gatchel et al., 2007; Lee et al., 2015; Proctor et al., 2000; Saariaho et al., 2012; Severeijns et al., 2001; Simmonds et al., 1996; Sorbi et al., 2006; Vetter et al., 2014; Vlaeyen et al., 1995; Zale et al., 2013). Additionally, individual perceptions of the painful trigger and response to treatment may have an impact (Moseley, 1999). Further, pain permanence beliefs, perceived self-efficacy to manage pain, and coping ability all contribute to level of PD (Arnstein, 1997; Ayre & Tyson, 2001; Casey, Greenberg, Nicassio, Harpin, & Hubbard, 2008; Knussen & McParland, 2009; Lee et al., 2015; Scudds & Østbye, 2001; Turk, 1996). Illegitimate motivational behaviors should also be considered, including malingering pain, drug misuse, and benefit-seeking actions (Aronoff, 1991; Bianchini et al., 2005; Etherton, 2014; Goldman & O'Neill, 1990).

Lastly, social contextual factors concern the environment that surrounds the individual during a period of PD. These include the atmospheres created at the systemic and local levels. Socioeconomic status, place of employment, and social support, such as the ability to receive rehabilitation services or disability compensation, are driven by systemic circumstances (Arnstein, 1997; Aronoff, 1991; Coggon et al., 2013; Etherton, 2014; Proctor et al., 2000; Teasell & Bombardier, 2001). At a local level, the family and social network's capacity to offer emotional or material support to help cope with the individual's PD can affect the experience (Bursch et al., 1998; Florence & Asken, 1994; Scudds & Østbye, 2001; Simmonds et al., 1996). Environmental context, including familial interaction, is instrumental in driving pain behavior and susceptibility to PD.

### *Antecedents*

Pain has been distinctly cited as the strongest predictor of PD (Arnstein, 1997). Before the development of PD, there must be a painful trigger that ignites an “unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (IASP, 2017). The painful experience may be induced by an injury, medical procedure, part of an acute flare of chronic pain, or ongoing pain-related condition.

Pain qualities may be described by intensity, location, distribution, frequency, and/or duration.

### Consequences

This concept analysis identified three major consequences of PD, including individual suffering, pain reactivity, and secondary loss. These three outcomes are synergistic and further promote PD. The central outcome of suffering, defined here as the individual appraisal of a distressing experience, is a direct result of the perception of physical pain and the subsequent conditions that are created in the wake of PD (Gatchel et al., 2007). Changes in mood and sleep pattern further contribute to a sense of hopelessness and suffering (Goldman & O'Neill, 1990; Scudds & Østbye, 2001; Severeijns et al., 2001; Vlaeyen et al., 1995). Quality of life may decline as a result of trying to manage functional losses as well as changing role expectations (Arnow et al., 2006; Scudds & Østbye, 2001).

The second consequence of PD is increased pain reactivity as individuals learn to cope with their discomfort and functional restrictions. Pain reactivity is defined as the individual's biobehavioral response to ongoing pain and resulting stress that contributes to the maintenance of disability (Davis, Zautra, Wolf, Tennen, & Yeung, 2015; Hamilton et al., 2008). These may include psychomotor, affective, or cognitive reactions. Examples are seen in pain behavior, kinesiophobia, maladaptive appraisals, increased preoccupation with pain and learned helplessness (Aronoff, 1991; Casey et al., 2008; Florence, & Asken, 1994; Turk, 1996; Vlaeyen et al., 1995).

Lastly, secondary loss is a concept detailed by Gatchel, Adams, Polatin, and Kishino (2002), but reflected throughout these findings. Secondary losses may be conceptualized as proximal and distal outcomes resulting from the indirect impact of PD. Gatchel et al. (2002) succinctly summarize that secondary loss “may infiltrate virtually all domains of life, including physical functioning and autonomy, social relationships, financial stability, employment and family roles, self-esteem, and even general world view” (p. 102).

### Model Case and Analysis

Charlene was an office assistant at a local law firm until 7 months ago when she herniated a disk in her spine while lifting a pile of boxes. This injury left her with a pinched sciatic nerve and persistent back pain. Although she was able to receive disability compensation for the first 3 months, the shooting pains down her back and numbness in her toes have limited her ability to sit at a desk and complete the tasks of her job. Charlene is now unemployed and has difficulty keeping up with her bills. She struggles most with the fact that she can no longer take her grandson to the park because she is afraid of making her pain worse. As a result, she sits at home all day and watches TV. Charlene was recently diagnosed with depression and has a difficult time finding enjoyment in her life.

This fictitious case clearly displays the attributes of PD as well as the consequences faced by an individual with PD. The inability for Charlene to play with her grandson and her subsequent depression may be considered secondary losses.

### Related Case and Analysis

Jack suffers from migraines and typically feels an aura before the next attack. When he experiences a migraine he often becomes nauseated and photophobic. Although he had tickets to a basketball game tonight, he felt an oncoming headache 3 hours before the game and decided not to go. After taking his medication, drinking fluids, and sleeping for 12 hours, Jack woke up the next morning without pain and returned to work.

This related case exhibits components of pain disability but does not display the attribute of challenging role expectations. This case is closely related to the concept of pain interference, which can be a component of someone's pain disability experience but does not define it (Wilson, 2014).

### Empirical Referents

Empirical referents are instances of the phenomenon that clearly measure the concept (Walker & Avant, 2011). Empirical referents of PD directly reflect the attributes and focus on the identification of the painful trigger, the physical and psychological consequences of the trigger, and the functional limitations exhibited by the individual. The key to considering a physical or psychological response to pain as PD is the identification of a functional loss, which may be expressed as limited mobility or psychological dysfunction. To measure this concept, it is also necessary to inquire about the degree to which social and occupational roles have been disrupted. This could be measured by days of missed work, reduction in participation of previously enjoyed activities, or changes in quality of life. Considering that PD is a personal experience, investigation of the empirical referents should be highly individualized in an attempt to identify which reflections of the attributes are displayed and the degree of disruption or impairment.

## Discussion

This concept analysis proposes a model of PD to improve clarity in identification, assessment and application in the clinical setting. These results indicate that PD is a fluid concept, characterized by the experiences of the individual. Bearing in mind the subjective nature of PD, the phrase also carries a note of abstraction. Considering all facets of the discussed concept, this analysis led to a definition of PD as the inability to maintain role expectations as the result of a painful trigger and subsequent physical and/or psychosocial dysfunction. Figure 2 shows the process of how a painful trigger can lead to PD when both attributes are present and the consequences that may result.

The findings of this analysis are directly related to previously developed models of pain and disability. In particular, the proposed definition of PD can be incorporated into the biopsychosocial framework, which provides a holistic understanding of the factors that contribute to the experience of pain and anchors the concept in a widely accepted model of pain (Gatchel et al., 2007; Smith, Fortin, Dwamena, & Frankel, 2013). Moreover, the defining attributes of PD identified in this analysis fit succinctly with the WHO conceptualization of disability. Specifically, the proposed definition of PD integrates the understanding of the person–environment interaction that both motivates and results from disability (WHO, 2011). The International Classification of Functioning, Disability and Health presents disability as a continuum, which helps to further understand pain disability as a process as opposed to a product (WHO, 2002).

Although this concept analysis attempted to cast PD in a broad light, it is not without limitations. The understanding of the concept was primarily taken from the clinical research perspective, implicating restriction in generalizability. Additionally, the process between the painful trigger and the development of PD remains undefined from this analysis and would benefit from an investigation of the role time may have in the process of developing PD. Further refinement of the definition may be pursued through qualitative analysis. Inclusion of patients who manage other forms of disability should also be considered.

### *Implications for Nursing*

PD, defined as the inability to maintain role expectations as the result of a painful trigger and subsequent physical and/or psychosocial dysfunction, is a clinically driven concept that interprets the ability of an individual with pain to interact with his or her environment. Following the steps of Walker & Avant (2011), this concept analysis provides a detailed look at what constitutes PD and proposes a model for increased comprehension and clinical application. Empirical referents are also given to improve recognition within the domain of nursing.

An improved understanding of PD could expand the nursing assessment and care of patients experiencing acute and/or chronic pain. By promoting this holistic framework, which encompasses biological, psychological, and social contributions, nurses can advance their knowledge and awareness of how an individual enters into this experience. Application of PD into the metaparadigm of nursing, which encompasses nursing, health, person, and environment, will further this understanding. Future research should continue the theory development of this model and compare application to previously validated instruments of PD. Exploring this concept further within diverse populations living with pain will help to elucidate potential mechanisms of persistent pain and may illuminate areas for intervention.

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