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# Patient empowerment: A cross-disease exploration of antecedents and consequences

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ABSTRACT

Emphasized by the World Health Organization as one of its key topics, patient empowerment (PE)—i.e., the set of self-determined behaviors based on patients' individual needs for developing autonomy and competence with their disease—is today regarded as a key component of a patient-centered approach to healthcare. Unfortunately, research lacks a clear understanding of the drivers of PE, its relationship to therapy compliance, and its role in different types of diseases. Using a large sample of 1622 patients suffering from chronic diseases, this study addresses these critical research gaps and provides three major contributions. First, by exploring the influence of PE antecedents (i.e., patients' health involvement, self-efficacy, and acceptance of physician authority), it provides specific recommendations on how to effectively manage PE (defined in terms of three dimensions: information search, knowledge development, and decision participation). Second, it demonstrates the importance of PE and its antecedents for affecting patients' therapy compliance and shows that, depending on the PE dimension, therapy compliance is either enhanced or reduced. By highlighting the ambiguous role of PE in therapy compliance, the study offers specific suggestions for healthcare stakeholders on how to maximize patients' compliance to recommended therapies. Third, the study provides important insights into the role of PE across different types of chronic diseases, offering practical recommendations on how to deal with patients depending on their particular disease.

## 1. Introduction

Identified by the World Health Organization as a high priority topic to be pursued globally (Delnoij & Hafner, 2013), patient empowerment (PE)—referring to the set of self-determined behaviors based on patients' individual needs for developing autonomy and competence with their disease—has increasingly become a key component of a patient-centered approach to healthcare. However, healthcare stakeholders, such as physicians, pharmaceutical companies, and public policy makers, are still uncertain about what drives PE and how to deal with it (Day, 2000). Understanding the major drivers of PE as well as its consequences could not only help improve the effectiveness of treatments for patients by increasing their therapy compliance. It could also considerably increase the success of drugs from pharmaceutical companies (Stremersch & van Dyck, 2009; Wosinska, 2005) and help insurance companies as well as publically funded healthcare systems reduce costs from therapy non-compliance and the treatment of subsequent evitable sequelaes (Veitch, 2010).

These benefits of PE, however, may vary heavily depending on the type of disease from which patients are suffering (Stremersch, 2008; Tattersall, 2011). Specifically, chronic diseases (i.e., diseases that are lasting for a longer period of time, such as three months or more (Galea, 2014; U.S. National Health Council, 2014) may cause patients to engage in their illness especially strongly, particularly compared to acute diseases (i.e., diseases that can be cured relatively quickly). Therefore, a better understanding of the role of PE across different types of chronic diseases may help healthcare stakeholders manage PE more specifically and effectively, thus enhancing its potential benefits.

Unfortunately, research on PE is scarce and provides almost no guidance on these issues. Exceptions in this area have mainly focused on describing the nature of PE (Aujoulat, d'Hoore, & Deccache, 2007; Ouschan, Sweeney, & Johnson, 2000, 2006). However, a clear and accepted conceptualization of the construct is still lacking. Prior studies (e.g., Gibson, 1991; Ouschan et al., 2000) have mainly relied on synthesizing prior definitions and conceptualizations, rather than providing a solid foundation based on existing theories (such as self-determination theory), despite the fact this has been repeatedly called for (e.g., Aujoulat et al., 2007; Zoffmann & Lauritzen, 2006). Further,

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prior definitions have not been clear on whether PE reflects attitudes, perceptions, or behaviors (e.g., Dunst & Trivette, 1996; Menon, 1999). In the absence of such clarity, also systematic identification of PE's antecedents is not feasible as by nature, attitudes, perceptions, and behaviors are subject to different types of drivers.

A few other researchers have begun discussing the potential advantages and disadvantages of PE, such as patient (non-)compliance (Broadstock & Michie, 2000; Camacho, de Jong, & Stremersch, 2014; Williams, Rodin, Ryan, Grolnick, & Deci, 1998), but there is little agreement on the univocal results. Moreover, knowledge about the major drivers of PE and its role in different contexts, such as different types of diseases, is still lacking. As a result, the major "challenge at the moment is [still] the lack of empirical evidence to support the benefits and best practices that should guide patient empowerment" (Camacho, Landsman, & Stremersch, 2010, p. 111).

Using a large and unique sample of 1622 patients suffering from a chronic disease (breast cancer, HIV/AIDS, diabetes, obesity, or obesity with diabetes) we address these critical research gaps on PE. To do so, we clearly root our PE conceptualization in Self-Determination Theory (SDT) and define PE as a set of behaviors across three dimensions (i.e., information search, knowledge development, and decision participation). This allows us to validly extend existing theory and to systematically identify drivers of consumer behavior, i.e., PE behavior. Consequently, our study provides three major contributions to the discipline. First, present the first study that, based on SDT, investigates major PE antecedents and explores how patients' perceptions of themselves, their health, and their physician (i.e., patients' health involvement, self-efficacy, and acceptance of physician authority) drive PE. Results show that the three PE dimensions are indeed strongly driven by patients' health involvement, self-efficacy, and acceptance of physician authority, but to varying degrees and by diverging directions (i.e., positively and negatively), allowing us to provide specific recommendations on how to manage PE more effectively.

Second, we demonstrate the importance of PE and its antecedents for influencing patients' therapy compliance. Depending on the PE dimension, we find that therapy compliance is either enhanced or reduced. Thus, we contribute to the discipline by highlighting the ambiguous role of PE in therapy compliance as well as by offering detailed recommendations for healthcare stakeholders on how to maximize patients' compliance to recommended therapies.

Third, this study is the first to provide insights into the role of PE across different types of chronic diseases, which allow us to provide specific recommendations to healthcare stakeholders on how to deal with patients depending on their particular disease. For instance, we find that stimulating PE is most important for improving therapy compliance of patients suffering from less severe diseases, such as obesity with diabetes, thus informing healthcare stakeholders to particularly encourage PE across these patients.

## 2. Development of the conceptual framework

### 2.1. Theoretical background of PE

We base our framework on Self-Determination Theory (SDT) (Deci & Ryan, 1985a, 1985b) which proposes how specific needs of individuals drive their self-intended (self-determined) behaviors. SDT states that human beings have basic psychological needs, such as the need for autonomy, which is the desire to experience one's behavior as self-endorsed or volitional, and the need for competence, which is the desire to experience satisfaction with exercising and extending one's capabilities and mastering challenging tasks. Individuals strive to satisfy these needs to increase their well-being and thus engage in certain behaviors that they perceive as self-determined (Deci & Ryan, 2000), such as information search or participation in decision making. These self-determined behaviors trigger subsequent behaviors, which individuals try to keep consistent with their previous actions and their underlying needs (Bem & Allen, 1974), such as complying with recommendations. Thus, individuals' desires for autonomy and competence may cause individuals' self-determined behaviors both directly and indirectly.

SDT further suggests that individuals' psychological needs vary depending on how individuals perceive themselves (e.g., in terms of self-efficacy) or others (e.g., physicians in terms of acceptance of physician authority) (Bandura, 1986; Deci & Ryan, 2000; Ryan & Deci, 2000). Accordingly, by influencing individuals' needs for autonomy and competence, these perceptions can cause behaviors geared toward satisfying these needs (Deci & Ryan, 1985a).

### 2.2. Development of PE model

Because SDT assumes that individuals develop inherent needs for autonomy and competence for managing challenging situations (e.g., Deci & Ryan, 2000), we argue that when suffering from a chronic disease, patients may develop inherent needs for autonomy and competence with respect to treatments intended to fight their disease and may engage in corresponding behaviors to satisfy these needs. We refer to these behaviors as PE. Specifically, PE is defined as a set of self-determined behaviors based on patients' individual needs for autonomy and competence, undertaken with the goal of actively dealing with their disease. In line with Ouschan et al. (2000, 2006), we suggest that PE consists of three dimensions: patients' information search and knowledge development (both addressing the need for competence) and patients' decision participation with regard to suggested treatments (addressing the need for autonomy). Specifically, *information search* is the degree to which patients systematically and actively collect disease- and treatment-related information from various information sources (e.g., personal meetings in self-help groups, books, the Internet, brochures) (Johnson, 2011). *Knowledge development* is the degree to which patients actively and easily organize and try to understand the information acquired about their disease, with the goal of achieving disease-related expertise to keep up with the physician (Funnell et al., 1991). *Decision participation* is the degree to which patients actively work with the physician to develop a treatment strategy and make treatment decisions (Camacho et al., 2014; Singh, Cuttler, & Silvers, 2004).

On the basis of SDT (Deci & Ryan, 1985b), we assume that PE is caused by three major antecedents that relate to patients' perceptions of their health, themselves, and their physician: health involvement, self-efficacy, and acceptance of physician authority. Specifically, *health involvement* denotes the importance patients attribute to their health in general and to the acts of maintaining this health (Zaichkowsky, 1985). *Self-efficacy* refers to patients' estimate of their capability and effectiveness in performing well in a specific task (Bandura, 1989). Finally, *acceptance of physician authority* is the degree to which patients deem a physician a person of respect and, owing to his or her status, right in what he or she says (Rigby, 1986). While we expect patients' acceptance of physician authority to reduce PE through decreasing their needs for competence and autonomy, we posit that health involvement and self-efficacy enhance PE through increasing those needs (see Fig. 1).

Because individuals generally tend to align previous and current actions (Bem & Allen, 1974), we assume that empowered patients show subsequent behavior that is consistent with their previous PE behavior. We refer to this subsequent behavior as *therapy compliance*, reflecting the extent to which the patient adheres to treatment recommendations and prescriptions targeted to his or her particular disease (Hausman, 2004). We expect that all three PE dimensions enhance therapy compliance. To account for the specific nature of the patients and their chronic disease, we add variables referring to patient demographics (age, gender, education level) and type of disease to our model.