



International Journal of Clinical and Health Psychology

www.elsevier.es/ijchp



ORIGINAL ARTICLE

Psychometric properties of an instrument to measure family disease management



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Received 15 January 2015; accepted 4 May 2015

Available online 6 June 2015

KEYWORDS

Family;
Disease management;
Confirmatory Factor
Analysis;
Instrumental study

Abstract An instrumental study of 392 households with sick or disabled members was conducted to analyze the psychometric properties of the Family Disease Management Scale. Three different models were analyzed using the Confirmatory Factor Analysis (CFA). One was a single-dimensional factor (family disease management) with 30 items; and two hierarchical models with three factors, which represent the dimensions, family support, family normalization and family participation, that placed the workload into another of higher order called family disease management, the first with 30 items and the second with 29. The CFA results showed that the latter 29-item model provided a better fit. The internal consistency analysis using the Cronbach alpha test showed a value of .93 for the complete scale and above .80 in the three subscales. This instrument may be useful to assess how families manage the illness or disability of its members, especially in clinical practice given the importance of the family as the primary caregiver. As well as in performing epidemiological studies, and in the field of management, planning and assistance.

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PALABRAS CLAVE

Familia;
manejo de la
enfermedad;
análisis factorial
confirmatorio;
estudio instrumental

Propiedades psicométricas de un instrumento para medir el control familiar de la enfermedad

Resumen Se realizó un estudio instrumental en 392 familias con miembros enfermos o discapacitados para estudiar las propiedades psicométricas de la Escala Manejo Familiar de la Enfermedad. Se analizaron tres modelos mediante Análisis Factorial Confirmatorio (AFC): uno con un factor (Manejo familiar de la enfermedad) con 30 ítems y otros dos jerárquicos, con tres factores, para las dimensiones apoyo familiar, normalización familiar y participación familiar, cuyos pesos se depositan en otro factor de orden mayor denominado Manejo familiar de la enfermedad, el primero con 30 ítems y el segundo con 29. Los resultados del AFC mostraron

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que el último modelo de 29 ítems obtuvo mejor ajuste. El análisis de la consistencia interna mostró valores de 0,93 para la escala completa y mayores de 0,80 en las tres subescalas. El instrumento podría usarse para valorar el manejo de la enfermedad o discapacidad de sus miembros por parte de las familias, especialmente en la práctica clínica, dada la importancia de la familia como cuidadora principal. También podría ser útil en estudios epidemiológicos o en la gestión y planificación sanitaria.

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Disease is a phenomenon that becomes part of family life producing structural, procedural and emotional changes that affect family health; this is understood as the family's ability to function and adapt to stressful life events, which include the illness or disability of any of its members (Gabriel, Figueiredo, Jácome, Cruz, & Marques, 2014; Knafl & Gilliss, 2002). Different authors have tried to explain the psychological phases that families go through when a member is diagnosed with a condition. In these situations families usually have a period of crisis that is followed by a period of post-crisis, which are influenced by different modulate variables, such as illness characteristics, family background, perception of situation, family burden, resources, and other capabilities including resilience, hardiness, coping, and other family characteristics such as cohesion, flexibility, communication, organization or mutually supportive relationships (Gabriel et al., 2014; Joseph, Goodfellow, & Simko, 2014; Knafl et al., 2011; Olson, 2011). The families tend to adapt to illness by way of normalization strategies to integrate this situation into daily family life. In this sense, both mastery and routinization of the treatment are important aspects of family's response to illness (Knafl & Gilliss, 2002).

The family disease management could be defined as daily behavior that families perform to manage and adapt when a member is diagnosed with a condition (Knafl et al., 2011) and aims at generating a positive family environment, with emotional stability and ways of coping appropriately that allow the patient and all family members to adapt to the crisis and obtain the services and resources needed. So that, families must initiate strategies aimed at coping with the impact of the illness or disability on the patient by offering support and assistance, at obtaining the necessary normalization to continue functioning and to minimize its consequences for other family members, and also must actively participate in the health care provided to the sick member (Ford, Courtney-Pratt, & Fitzgerald, 2012; Lima-Rodríguez, Lima-Serrano, & Sáez-Bueno, 2009).

Conceptual definition of the construct under assessment

Nursing outcomes classification (NOC) for family health domain, was used as a reference, from which family support during treatment, family normalization and family participation in professional care outcomes were

selected (Lima-Rodríguez, Lima-Serrano, Jiménez-Picón, & Domínguez-Sánchez, 2013). NOC is a standardized classification of health outcomes, which has previously been used in designing clinometric instruments (Morales-Asencio et al., 2015). We considered that family disease management should be oriented to achieve the named outcomes given that they refer to key elements related to disease management, i.e., sick person, his/her family, and family participation in professional care.

Family support is related to the functions of support and care, providing for the patient's well-being and independence, and assisting in disease surveillance, decision-making and implementation of appropriate actions. The family should maintain good communication and empathy, provide information, material and emotional assistance, thus meeting the patient's basic needs. Previous studies have shown that the people with higher levels of family support have better adherence to the regime, better management of disease and lower hospitalization rates (Strom & Egede, 2012).

Family normalization starts acknowledging the new condition of the sick or disabled member and the potential changes needed to manage this situation (Knafl & Gilliss, 2002). It is related to changes in family functioning and organization, in which family has to be flexible in the performance of family roles, in modifying the family routine and housing conditions if necessary, and adjust their resources and apply for help for the extended family as well as the existing community social services (Ávila-Jiménez, Cerón, Ramos-Hernández, & Velázquez, 2013). Previous research showed the importance of including the care of the sick or disabled member in daily family life, especially for sick children and chronic disease (Emiliani, Bertocchi, Poti, & Palareti, 2011).

Family participation in the care process is particularly necessary in the case of children, disabilities or mental illness, terminally ill patients, etc., where the family should be involved in taking decisions about who to consult, when or where to go for treatment. The family is responsible for managing the sick person's day to day life, accompanying them regularly to the care professional or during hospitalization, providing key support to the professional in the communication with the patient, and identifying the factors that affect attendance and the attitudes and behaviors that are most effective for coping with the problem (Rosland et al., 2013; Wolff & Roter, 2011); and the participation of the family in the care plan is also a positive motivator

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