



## ORIGINAL ARTICLE

# Tools to assess living with a chronic illness: A systematic review<sup>☆</sup>



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### Abstract

**Objective:** To analyse the currently available instruments to assess living with a chronic illness and related aspects.

**Method:** A review of the evidence was made using the databases: Medline, CINAHL, PsycINFO, Cochrane Library, Embase and Cuiden. The criteria that limited the search were: the language, English and/or Spanish and studies carried out in an adult population. Years of article publication were not used as a limit.

**Results:** A total of 16 instruments were identified and analysed that apparently measured the concept of living with a chronic illness and/or related aspects. According to the name of the instrument, four seemed to evaluate the concept of living with a chronic illness while the rest of the instruments evaluated aspects intrinsically related to the concept of "living with", such as attributes or the meaning of living with a chronic illness.

**Conclusions:** Different instruments were identified to evaluate daily living for the chronically ill patient, as well as related aspects. According to this review, further validation studies are required in other populations and/or contexts in order to achieve valid and reliable instruments that could be used in clinical practice.

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**PALABRAS CLAVE**

Convivencia;  
Enfermedad crónica;  
Adaptación;  
Revisión;  
Enfermería

**Instrumentos para valorar la convivencia del paciente con un proceso crónico: una revisión sistemática****Resumen**

**Objetivo:** Analizar los instrumentos existentes en la actualidad que evalúan la convivencia del paciente con un proceso crónico o aspectos relacionados con la convivencia.

**Método:** Se llevó a cabo una revisión sistemática de la evidencia disponible en las bases de datos: Medline, CINAHL, PsycINFO, Cochrane Library, Embase y Cuiden. Los criterios que limitaron la búsqueda fueron: el idioma, inglés y/o español y los estudios llevados a cabo en una población adulta. No se aplicó límite de años de publicación de los artículos.

**Resultados:** Se identificaron y analizaron un total de 16 instrumentos que potencialmente evaluaban la convivencia con un proceso crónico y/o aspectos relacionados con el mismo. En cuanto al nombre del instrumento, 4 evaluaban el concepto convivencia con un proceso crónico, mientras que el resto de instrumentos evaluaban algún aspecto de la convivencia o el significado de convivir con un proceso crónico.

**Conclusiones:** Se han identificado diferentes instrumentos para evaluar el día a día del paciente con un proceso crónico, así como aspectos relacionados con el mismo. Después de esta revisión, se considera necesaria la realización de futuros estudios de validación en otras poblaciones y/o contextos para lograr instrumentos válidos y fiables que puedan ser empleados en la práctica clínica.

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**What do we know?**

Living with a chronic illness is complex and requires holistic, person-focussed care. Nurses play a key role in establishing and assessing the daily existence of patients with chronic conditions. To that end measuring scales are essential to assess how patients cope with chronic illness.

**What does this paper contribute?**

This article presents a critical review of the different measuring scales in the literature to assess living with a chronic disease, and relevant aspects. This will provide nurses with more knowledge of the scales available to evaluate different aspects of the daily lives of chronically ill patients, and be able to use them in their daily clinical practice.

**Introduction**

In developed countries, chronic illness causes the highest number of deaths and resource consumption.<sup>1</sup> Furthermore, projections for the years ahead predict that this situation will get progressively worse, creating greater demand for increasingly more diversified and individual needs and services.<sup>1,2</sup> Inevitably, this problem has resulted in new approaches in terms of national and European health

policies<sup>1,2</sup> that advocate directing health services towards holistic care that centres on the person and not the disease. To that end, social and healthcare professionals must focus on the perspective of the patient in living with their disease in order to plan individualised interventions, and examine their daily reality to help them cope with their disease. Thus, social and healthcare professionals will be able to provide holistic and quality care, to suit each patient's specific needs.<sup>3</sup>

Living with a chronic illness is a complex, cyclical, dynamic, constantly changing, contextual and multi-dimensional process that entails acceptance, coping, self-management, integration and adjustment to the disease.<sup>4</sup> Equipped with this knowledge, social and health professionals, and more specifically nurses, play a key role in this process of living with chronic illness, since they can facilitate a positive approach to the condition, and improve patients' quality of life and wellbeing.<sup>3,4</sup> Moreover, they can help to avoid negative potential complications such as denial or failing to cope with the disease.<sup>4</sup> As a consequence, the chronically ill patient will be more autonomous in their daily living with the disease, reduce consultations with clinical specialists and will become expert in their own care, improving their quality of life and wellbeing.<sup>3,4</sup> Tools that can reveal how patients are coping with a chronic disease will facilitate this process. Taking into account the directives of the Ministry of Health, Social Services and Equality<sup>1</sup> on the importance of providing holistic care for chronically ill patients, a knowledge of tools and their inclusion and use in nurse consultations is essential to deal with aspects beyond the disease and its treatment. However, many social and health professionals are currently unaware of the tools available for use in daily clinical practice to measure in a holistic way how patients are living with their disease, or any

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