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Title page**Measuring empowerment among people living with HIV: A systematic review of available measures and their properties**

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Suggested running head

Measuring empowerment in HIV

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Abstract

A systematic review was conducted to identify and appraise measures of empowerment used in peer-reviewed research with people living with HIV. Thirty articles reporting on 12 scales were identified via keyword and citation searches of electronic databases and hand searching of reference lists. The instruments captured a wide range of constructs, including self-efficacy, perceived knowledge/information seeking, self-management behaviours, belief in an active patient role and tolerance of uncertainty. While the majority of instruments were focused exclusively on self-efficacy to manage HIV, the Patient Activation Measure (PAM-13 and PAM-22) and the Health Empowerment Inventory were broader in scope. Most of the identified measures had acceptable construct validity, however there were insufficient data to determine the reliability or responsiveness of many of the scales. The findings highlight the need for a more concrete definition of empowerment and for further validation of existing measures with people living with HIV.

Keywords: empowerment; HIV; systematic review; self-efficacy; patient activation

Introduction

Patient empowerment is increasingly recognised as an important outcome of healthcare interventions and policy (Bravo et al., 2015). It has been postulated that empowered individuals will make more rational decisions about their health, be less dependent on health care services and use services in a way that is more cost-effective compared to less empowered individuals (McAllister, Dunn, Payne, Davies, & Todd, 2012). Patient empowerment has been associated with adherence to medication across a range of long-term conditions (Náfrádi, Nakamoto, & Schulz, 2017).

The concept of patient empowerment may be of particular interest in the context of HIV, where there has been a history of involvement of people living with HIV (PLWH) in the development of healthcare services and treatment (The Kings Fund, 2017). Measuring patient empowerment as an outcome may help healthcare providers and researchers to evaluate the impact of policy changes and interventions. However this is not straightforward as there is a lack of conceptual clarity regarding empowerment in the literature (Alpay, van der Boog, & Dumaij, 2011; McAllister et al., 2012; Pulvirenti, McMillan, & Lawn, 2014; Risling, Martinez, Young, & Thorp-Froslie, 2017). A recent study drawing on published definitions of empowerment and interviews with key stakeholders identified a range of indicators of patient empowerment, including patient states and capacities (e.g. self-efficacy, knowledge, skills) and patient behaviours (e.g. taking an active role in decision making) (Bravo et al., 2015).

Given the lack of agreement on the core components of empowerment, it is unsurprising that a systematic review of empowerment questionnaires found a wide variation in terms of the constructs measured (Barr et al., 2015). This review was narrow in focus, only including questionnaires that specifically purported to measure empowerment and not overlapping constructs such as patient activation or self-efficacy. As a result, only two empowerment measures used in studies with PLWH

were identified. The aim of this study was to conduct a more comprehensive review of questionnaires used to measure empowerment among PLWH and to explore their underlying constructs and psychometric properties.

Method

Papers were identified through searching online databases, reference lists of relevant papers and a citation search using the primary validation paper of each empowerment measure identified (Web of Science and Google Scholar). Search engines and terms used are shown in Table S1.

Papers were included if the study measured patient empowerment or an overlapping construct (e.g. patient activation, self-management self-efficacy) and if more than 50% of the sample comprised PLWH. Papers were excluded if the study focused on children, was an unpublished thesis or if empowerment was assessed in relation to a single behaviour (e.g. adherence to medication, exercise).

Two researchers (JC and VC) independently extracted the data from the identified papers and from the primary validation paper of each empowerment measure. Psychometric quality criteria assessing eight domains (content validity, internal consistency, criterion validity, construct validity, reproducibility, responsiveness, floor and ceiling effects, interpretability) were applied to the primary validation papers (Terwee et al., 2007).

Results

Thirty relevant studies were identified (Figure 1), reporting on the use of 12 different empowerment measures. Characteristics of the studies are summarised in Table S2. Six studies (20%) reported on the development of a measure, while the remaining 24 (80%) reported on the use of an existing measure.

Figure 1 here

Table 1 provides an overview of the 12 measures. All but one measure (HCEI) included items on self-efficacy. Many addressed multiple aspects of self-efficacy, including perceived capacity to manage symptoms, manage treatment, communicate effectively with health professionals, obtain information, access support and manage emotional wellbeing. Three measures assessed perceived knowledge/information seeking (HCEI, PAM-22, PAM-13), three assessed self-management behaviours (HCEI, PAM-22, PAM-13), three assessed belief in an active patient role (HCEI, PAM-22, PAM-13) and one assessed tolerance of uncertainty (HCEI).

Table 1: Overview of included measures

Measure	No. Items	Target population	Empowerment construct assessed				
			Self-efficacy	Perceived knowledge/ information seeking	Self-management behaviours	Belief in an active patient role	Tolerance of uncertainty
Chronic Disease Self-Efficacy Scales (Lorig et al., 1996)	33	Generic	+				
Health Care Empowerment Inventory (HCEI) (Johnson, Rose, Dilworth, & Neilands, 2012)	8	Generic		+	+	+	+
HIV Self Efficacy Questionnaire (Shively, Smith, Bormann, & Gifford, 2002)	34	Adapted for HIV	+				
HIV Symptom Management Self-Efficacy for Women Scale (Webel & Okonsky, 2011)	9	Adapted for HIV	+				
HIV Symptom Management Self-Efficacy Scale (Eller et al., 2014)	10	Adapted for HIV	+				
Patient Activation Measure (13 items) (PAM-13) (Hibbard, Mahoney, Stockard, & Tusler, 2005)	13	Generic	+	+	+	+	
Patient Activation Measure (22 items) (PAM-22) (Hibbard, Stockard, Mahoney, & Tusler, 2004)	22	Generic	+	+	+	+	
Perceived HIV Self-Management Scale (Wallston, Osborn, Wagner, & Hilker, 2011)	8	Adapted for HIV	+				
Self-Efficacy Inventory (Ironson et al., 2005)	8	HIV specific	+				
Self-Efficacy to Manage Chronic Disease Scale (Ritter & Lorig, 2014)	6	Generic	+				
Strategies Used by Patients to Promote Health scale (Lev & Owen, 1996)	29	Generic	+				
Treatment Self-Efficacy (Houston & Fominaya, 2015)	20	HIV specific	+				

Table 2: Psychometric quality of measures based on information provided in the validation papers (Terwee et al., 2007)

Measure (author)	Content validity	Internal consistency	Criterion validity	Construct validity	Reproducibility (Agreement)	Reproducibility (Reliability)	Responsiveness	Floor and ceiling effects	Interpretability
Chronic Disease Self-Efficacy Scales	+	?	0	+	?	0	0	+	0
Health Care Empowerment Inventory (HCEI)	-	+	0	+	0	0	0	0	?
HIV Symptom Management Self-Efficacy Scale	-	?	0	?	0	0	0	0	0
HIV Self-Efficacy Questionnaire	+	-	0	+	0	0	0	0	0
HIV Symptom Management Self-Efficacy for Women Scale	-	?	0	-	0	0	?	0	0
Patient Activation Measure (13-items) (PAM-13)	+	?	0	+	0	0	0	0	0
Patient Activation Measure (22-items) PAM-22	+	+	+	+	?	0	0	0	0
Perceived HIV Self-Management Scale	0	?	0	?	0	0	0	0	0
Self-Efficacy Inventory	0	?	0	?	0	0	?	0	0
Self-Efficacy to Manage Chronic Disease Scale	+	+	0	+	0	0	?	+	0
Strategies Used by Patients to Promote Health	+	+	0	+	?	?	0	0	0
Treatment Self-Efficacy	0	?	0	?	0	0	0	?	?

Rating: + clear description/met design/evidence criteria; ? indeterminate (doubtful design/method or lack of clear description); - lack of evidence; 0 no information provided

None of the primary validation papers reported on all quality criteria [Terwee et al. (2007) (Table 2). Most reported on internal consistency, however only a third reported both factor analysis with a sufficient sample size and Cronbach's alphas within acceptable levels. Half met the criteria for content validity, which included involving patients in the development of the scale. Acceptable construct validity was reported for the majority of measures. With regard to reliability, most papers only reported internal consistency but did not conduct test-retest reliability. Few papers provided information on agreement, floor and ceiling effects, interpretability, criterion validity or responsiveness.

Additional validation data were extracted from the 30 studies identified in this review (Table S2), predominantly supporting the findings of good internal consistency (Cronbach's alphas) and construct validity (questionnaire scores were associated with a range of variables including adherence to ART, CD4 count, viral load and primary care visits). Further information was also provided on the ability of four of the questionnaires to detect change over time (PHIVSMS, Chronic Disease Self-Efficacy Scales, PAM-13 and SE Inventory).

Discussion

Thirty articles were identified utilizing 12 questionnaires to measure patient empowerment in PLWH. Similar to systematic reviews of empowerment measures across chronic illnesses (Barr et al., 2015; Herbert, Gagnon, Rennick, & O'Loughlin, 2009), the questionnaires captured a variety of constructs. We categorised these constructs into the following domains: self-efficacy; perceived knowledge/ information seeking; self-management behaviours; belief in an active patient role and tolerance of uncertainty.

Only one questionnaire was explicitly developed to measure patient empowerment (HCEI). The majority focused exclusively on self-efficacy. While self-efficacy is an important part of patient

empowerment, most definitions describe empowerment as a multidimensional construct (Alpay et al., 2011; McAllister et al., 2012; Pulvirenti et al., 2014). Three questionnaires were broader in scope (PAM-13, PAM-22 and HCEI), each encompassing three additional constructs (e.g. perceived knowledge/information seeking, self-management behaviours, belief in an active patient role or tolerance of uncertainty).

The extent to which the psychometric properties of the questionnaires had been assessed varied. While most had acceptable construct validity, there were insufficient data to determine reliability. Assessing change in patient empowerment is likely to be important when evaluating the effectiveness of interventions, yet most studies were cross-sectional and had not assessed questionnaire responsiveness.

In conclusion, a variety of questionnaires have been used to measure empowerment in PLWH, however the majority focus on self-efficacy, which is only one aspect of this multidimensional construct. There is a need for further research in to determine the reliability and responsiveness of many of the measures. Ultimately the choice of one measure over another is likely to be influenced by the purpose of the assessment and the domains most relevant to the specific research question.

Contributorship

Jennifer Whetham and the EmERGE-consortium conceived of the study and the final design of the review was agreed between Jennifer Whetham, Richard Harding, Jane Clatworthy and Vanessa Cooper. The systematic review was conducted by Jane Clatworthy and Vanessa Cooper in consultation with Richard Harding and Jennifer Whetham. All authors contributed to writing and reviewing the article.

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