



Psychometric properties of a caregiver illness perception measure for caries in children under 6 years old



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ARTICLE INFO

Article history:

Received 12 October 2015

Received in revised form 4 January 2016

Accepted 5 January 2016

Keywords:

Behavioral sciences

Caries

Dental health survey

Psychology

Reliability

Validity

ABSTRACT

Objective: Based on the Common-Sense Model of Self-Regulation (CSM), the Revised Illness Perception Questionnaire (IPQ-R) was developed to measure patients' perceptions of their chronic medical illness. Such a measure does not exist for dental conditions. This study describes psychometric properties of the IPQ-R for Dental (IPQ-RD) for parent/caregivers of children under 6 years of age.

Methods: Parent/caregivers ($n = 160$) of children aged <6 years attending a pediatric dental clinic completed the IPQ-RD and a questionnaire assessing their socio-demographics, dental anxiety, oral health self-efficacy, and child's preventive dental visits. Dental charts were abstracted for child's decayed, missing, filled teeth (dmft) information. The 33-item IPQ-RD was tested for internal (construct, discriminant) and external validity (concurrent, convergent, discriminant) and reliability (internal consistency).

Results: Confirmatory factor analysis demonstrated that the eight-factor model in accordance with the CSM framework (identity, consequences–child, consequences–caregiver, control–child, control–caregiver, timeline, illness coherence, emotional representations) had good construct validity based on significant factor loadings and acceptable to excellent model fit (RMSEA = 0.078, CFI = 0.951). Concurrent validity was demonstrated by significant negative correlations and higher mean factor scores for five constructs for children without dental visits indicating inaccurate caregiver perception of cavities. Discriminant validity was suggested by non-relationship with external measures (dental anxiety, self-efficacy). Internal consistency of six IPQ-RD constructs was excellent (Cronbach's alpha >0.74).

Conclusion: The IPQ-RD is a valid and reliable measure to assess parent/caregivers' representation of young children's cavities with potential to be a valuable risk assessment tool for oral health behavioral research.

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1. Introduction

Dental caries (tooth decay, cavities) continues to be disproportionately prevalent among poor and minority children [1]. Recent national estimates in the U.S. indicate that early childhood caries (ECC) continues to be problematic with prevalence at 23% and untreated tooth decay at 10% among <6 year olds [1]. Untreated primary tooth decay is a strong predictor of future caries indicating its chronic nature [2,3]. Nevertheless, most low-income parent/caregivers see dental diseases as acute: only dealt with when there is pain or visible decay [4]. Such beliefs lead to poor parent/caregiver behaviors and are associated with failure to seek dental care for their children [5], leading to untreated caries [6,7].

Illness representation, a framework of the Common-Sense Model of Self-Regulation (CSM), posits that patient's/caregiver's personal beliefs about a specific illness and its treatment and their emotional response

towards it affect disease outcomes, primarily via coping responses [8,9]. Individuals form a cognitive and emotional representation/perception based on the abstract and concrete sources of information available to them in order to self-manage their own or (if they are the caregiver) the patient's illness. These sources of information include *cultural knowledge* of the illness; *information from doctor/dentist* or parent; and *illness threat from past/current experiences* with the disease [10]. Systematic reviews have empirically demonstrated that illness perception significantly predicts a range of medical and psychological health outcomes, including medication adherence and health-related quality of life [11–15]. Behavioral interventions that have been developed to change illness perception have been instrumental in improving health outcomes, such as increased cardiac rehabilitation rates and medication adherence [16,17].

In oral health, measures currently available assess caregivers' factual knowledge, attitude or beliefs about children's dental caries [18–20] and parent-reported young child's oral health-related quality of life [21,22] which are mostly based on the social cognitive and health behavior theories. However, these measures have had limited utility as they are not comprehensive and focus mainly on the *consequences* of dental caries and treatments. The CSM is unique from other social cognitive and health behavior theories in three ways: (1) it requires an individual's perspective together with his/her emotional representation of the

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disease [23]; (2) it provides a dynamic systems framework with feedback to better understand how caregivers develop a common-sense approach to managing their children's caries threat [24]; and (3) it builds on a reasoning process by which a caregiver, who faces an oral health threat (for themselves or their child) develops a cognitive and emotional representation (personal model of oral disease) which in turn drives coping responses, oral health behaviors, and oral disease outcomes (e.g., caries, oral health quality of life). Since parent/caregivers are the gatekeepers of their children's oral health, it is important that they have an accurate representation of the disease that moves them from a disorganized (i.e., acute - disease is present only with symptoms such as pain) to an organized (i.e., chronic - disease is present even without symptoms) model to engage in adequate self-management strategies [23]. Like any theory, the utility of the CSM model is only feasible after an accessible measurement scale has been developed [25]. Based on the CSM, the Illness Perception Questionnaire (IPQ) was developed to assess five cognitive domains (identity, cause, consequences, control, timeline) of an illness [26]. The Revised Illness Perception Questionnaire (IPQ-R) enhanced the theoretical underpinnings of the original IPQ by including two additional domains - illness coherence and emotional representations [8]. The IPQ-R has been adapted for other illnesses with good reliability [27–29] and validity [30–32]. In causal pathway analysis, illness perception has been identified as an effective mediator [33,34].

Currently, there is lack of such a theory-based measure to understand how parent/caregivers, in response to a child's illness threat, form cognitive and emotional representations/perceptions of the child's oral disease and what guides their coping and action planning. Misconceptions about dental caries (e.g., unimportance of baby teeth, lack of understanding about its chronic nature) can impact coping and action planning. An appropriate measure is particularly important for caregivers of children under 6 years of age because it can identify targets for intervention to restructure disease beliefs and misconceptions about caries. Thus, we developed a parent/caregiver version of the Illness Perception Questionnaire Revised for Dental (IPQ-RD). The objective of this study was to assess the psychometric properties of the IPQ-RD in terms of validity and reliability for use in caregivers of children under 6 years of age with and without cavities.

2. Methods

2.1. Development of the IPQ-RD

The Patient-Reported Outcome Measurement Information System (PROMIS®) Instrument Development and Validation Standards (Version 2.0, May 2013) served as a guideline for psychometric assessment of the IPQ-RD. The IPQ-RD measure was developed with input from three content experts (dentist, psychologist, and epidemiologist) and involved changes to the structure and organization of the IPQ-R items to make it more relevant to dental caries. It was specifically modeled after a version of the IPQ-R for individuals providing care to a relative with a chronic medical illness [35] - i.e., the control and consequences dimensions were each divided into caregiver- and child-related items.

The initial version of the IPQ-RD had 10 dimensions and 37 items at the 6th-grade Flesch-Kinkaid readability level. It included the following dimensions or constructs: identity (2 items), consequences-child (8 items), consequences-caregiver (6 items), control-child (5 items), control-caregiver (4 items), timeline-acute/chronic (4 items), timeline-cyclical (2 items), illness coherence (2 items), emotional representations (4 items), and cause (1 item with multiple statements) scored on a 5-point Likert scale response format (ranging from strongly agree to strongly disagree). This initial version of the IPQ-RD was tested with 84 parents/caregivers of K-2nd grade children from an urban school district who were participating in a pilot study to develop the IPQ-RD instrument and behavioral interventions.

A mixed-methods approach was used as follows: For *qualitative*, semi-structured interviews of parent/caregivers using cognitive interviewing techniques [36] assessed the IPQ-RD's content validity. Caregivers provided detailed feedback on the IPQ-RD's readability and clarity. Caregiver interviews were transcribed and responses coded using Atlas.ti (Version 7, Berlin, Germany). The coded responses were later summarized and used to refine the IPQ-RD; for *quantitative*, confirmatory factor analysis (CFA) assessed the construct validity of the IPQ-RD constructs. The CFA confirmed a six-factor model with 31 items (consequences-child, consequences-caregiver, control-child, control-caregiver, timeline-acute/chronic, and emotional representations) that marginally fits the data (RMSEA = 0.104). Because a minimum of three items is required to estimate a factor via maximum likelihood [37], three constructs-identity, timeline-cyclical, and illness coherence-were not included in the CFA model. The marginal model fit was mainly influenced by negatively worded items (i.e., reverse-coded). For reliability, Cronbach's alpha assessing the IPQ-RD's internal consistency showed that four of the six constructs had alpha scores ≥ 0.70 . Test-retest reliability (21 participants completed the questionnaire a second time) was moderate (weighted Kappa 0.45, 95% CI: 0.42–0.49).

The initial testing (Appendix) indicated that the IPQ-RD had to be revised (Table 2). Reverse-coded items were unreversed by rephrasing negatively worded items (e.g., #13 "My child's tooth decay has not had much effect on my life") into positively worded items (e.g., #10 "Cavities in my child have a big impact on my life"). In a few cases, though, negative wording was necessary to ensure that all items were stated in the same direction, e.g., item #12 ("My child's tooth decay has become easier for me to live with") was rephrased as item #11 ("I cannot easily live with my child's cavities"). Double-barreled, vague, or unclear items were modified, e.g., item #19 ("My child's treatment will be effective in curing their tooth decay") was rephrased as item #16 ("My child's treatment will help make his/her cavities better"). In the case of item redundancy, i.e., items that are essentially paraphrases of each other (e.g., items #4 "My child's tooth decay has had major consequences on their life" and #5 "My child's tooth decay has not had much effect on their life"), one of the items was removed (in this case, #4). The original version of the 37-item IPQ-RD was revised to the current 33-item version.

2.2. Study design and participants

In this study, the 33-item version of the IPQ-RD was tested in a separate sample of 160 parent/caregivers with a child <6 years old who were part of an ongoing case-control study investigating the relationship between illness perception and early childhood caries (ECC). The caregiver participants were recruited from a pediatric dental clinic at an urban hospital in Cleveland, Ohio. The study was approved by the University Hospitals Case Medical Center Institutional Review Board and parent/caregivers signed the informed consent form. This manuscript conforms to the STROBE guidelines for observational studies.

2.3. Data collection

Illness Perception Questionnaire-Revised for Dental (IPQ-RD: 33 items): evaluated parent/caregivers' cognitive and emotional representations of their children's dental caries. The cognitive dimensions included: *identity*, labeling of dental caries and its symptoms; *consequences (child, caregiver)*, belief about the impact of caries physically and socially; *cure or controllability (child, caregiver)*, belief about whether caries can be cured or kept under control; *timeline*, beliefs about caries being acute, chronic, or cyclical in nature; *illness coherence*, whether the caregiver has a clear understanding of caries and symptoms associated with caries; and *cause*, perception of the underlying cause of caries. *Emotional representation* is the caregivers' emotional response (e.g., worry, anger) to their child's dental caries. Each item was scored on a 5-point Likert scale (strongly agree to strongly disagree) with a poorer

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