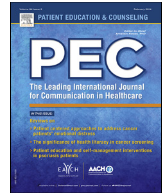
Patient Education and Counseling 95 (2014) 406–413

Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou



Patient Perception, Preference and Participation

Relatives' perspectives on the quality of care in an Intensive Care Unit: The theoretical concept of a new tool

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ARTICLE INFO

Article history:
Received 6 November 2013
Received in revised form 12 March 2014
Accepted 22 March 2014

Keywords:
Consumer Quality Index
CQI
Quality of care
Quality assessment
Satisfaction
communication
Intensive Care Unit
Critical care
Relatives
Family support
Health care surveys

ABSTRACT

Objective: To examine the potential of a questionnaire (CQI 'R-ICU') to measure the quality of care from the perspective of relatives in the Intensive Care Unit (ICU).

Methods: A quantitative survey study has been undertaken to explore the psychometric properties of the instrument, which was sent to 282 relatives of ICU patients from the Erasmus MC, an academic hospital in Rotterdam, the Netherlands. Factor-analyses were performed to explore the underlying theoretical structure.

Results: Survey data from 211 relatives (response rate 78%) were used for the analysis. The overall reliability of the questionnaire was sufficiently high; two of the four underlying factors, namely 'Communication' and 'Involvement', were significant predictors. Two specific aspects of care that needed the most improvement were missing information about meals and offering an ICU diary. There is a significant difference in mean communication with nurses among the four wards in Erasmus MC.

Conclusions: The CQI 'R-ICU' seems to be a valid, reliable and usable instrument. The theoretical fundament appears to be related to communication.

Practice implications: The newly developed instrument can be used to provide feedback to health care professionals and policy makers in order to evaluate quality improvement projects with regard to relatives in the ICU.

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1. Introduction

Severe illness and subsequent admission of a family member or friend to an Intensive Care Unit (ICU) can have a serious impact on the psycho-social well-being of the relatives/friends. They can become confused and anxious, may experience severe sadness and depression or even develop a 'Post intensive care syndrome-family' [1–3]. The mental distress may be caused by the gravity of the situation, uncertainty about the course of the medical situation or the unexpected death of the patient. In addition, the ICU environment with a multitude of unfamiliar equipment, sounds, smells, staff and other patients might contribute to the level of stress. Health care providers should develop the skills to observe this stress to address the needs of relatives.

Relatives could have an important role in the physical and psycho-social recovery process of the ICU-patient [4,5]. They can support their beloved ones in an emotional, cognitive and practical way, provided that they themselves are able to cope with the stressful situation. They also might enhance the trust of the patient, a significant aid in the recovery process [6]. Most ICU-patients are not able to receive information or make decisions, due to the severity of their medical condition and/or the administration of sedative medication, leaving the relatives as surrogate decision makers [7]. This role requires a careful communication process that begins immediately after hospitalization.

Both nurses and doctors seem to underestimate the relatives' need for information [8–10]. Inadequate communication might lead to dissatisfied patients and/or relatives, resulting in formal and informal complaints about the provided care [11]. Moreover, ideally patient and family communication leads to an elevated level of knowledge, less fear and decreases in insecurity and stress [12]. From the relatives' perspective, communication is assumed to

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http://dx.doi.org/10.1016/j.pec.2014.03.019
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be one of the most important factors in the perceived quality of care in the ICU, whereas most caregivers think the physical aspects of patient care are the most important factors for the relatives of ICU patients.

Currently, there is insufficient insight into the quality of care offered to relatives in the ICU because an evidence-based measurement tool is missing in the Netherlands [13]. The 'Family Satisfaction in the ICU Survey' (FS-ICU) [14] and the 'Care Family Satisfaction Survey' (CCFSS) [15] were developed previously to measure the satisfaction of relatives in the ICU. However, these instruments were developed in non-Dutch situations. It seems reasonable that some items will be experienced as more or less important by relatives from different countries or even continents [16]. Moreover, although these instruments proved to be valid and reliable, the utilized concept of satisfaction might raise some bottlenecks such as ceiling effects, cognitive dissonance and socially desirable answers [17]. A discrepancy model, which describes satisfaction as a result of expectation minus the perceived experience, could overcome these problems [18]. Accordingly, developing a measurement instrument to establish the quality of care to relatives in ICUs in the Netherlands is a logical follow-up of these previous studies.

The development of the new instrument was built upon the Consumer Quality Index (CQI), which is a scientific and standardized method to determine the experiences of customers with the provided care [19–21]. The CQI instruments are theoretically founded by the CAHPS® instruments and QUOTE® methodology [22], both based on a discrepancy model [23]. To meet a sufficient quality of care, the expectations regarding the quality should be in accordance with the perceptions of the actual experiences according to these methodologies [24,25]. Although this method judges the quality of care, there is no instrument under the umbrella of the CQI instruments available addressed to relatives in the ICU. Therefore, a CQI 'Relatives on Intensive Care Unit', in short CQI 'R-ICU', was accordingly developed within the Netherlands as a co-creation among HAN University of Applied Sciences, three hospitals (Erasmus MC, Rotterdam, Gelderse Vallei and Kennemer Gasthuis), and Open University of the Netherlands [26].

The theoretical framework of the CQI 'R-ICU' is partly derived from the 'Theoretical Model for Patient Focused Communication' [27], which is applied to the communication between relatives and caregivers. This model distinguishes between an instrumental need, 'the need to know and to understand', and in an emotional need, 'the need to be known and understood'. Subsequently, the caregivers should respond appropriately to these needs to influence coping mechanisms of the relatives. Communication is stated to consist of content aspects, such as information on medical treatment or visiting hours, and relational aspects such as respectfulness and hopefulness [28]. Both clusters of elements are expected to influence the quality of care given to relatives. This manuscript describes the theoretical framework and developmental process of the CQI 'R-ICU' instrument and explores the psychometric properties of this new tool.

2. Methods

The research protocol for the study was approved by the Medical Ethics Committee (MEC) of Erasmus MC, Rotterdam (MEC-2011-189). The committee judged that the study complied with the Dutch law on Medical Research in Humans (WMO).

2.1. Study design

The total process of development and validation was performed by the HAN University of Applied Sciences. The overall research plan, which was based on the Manual CQI, consisted of qualitative

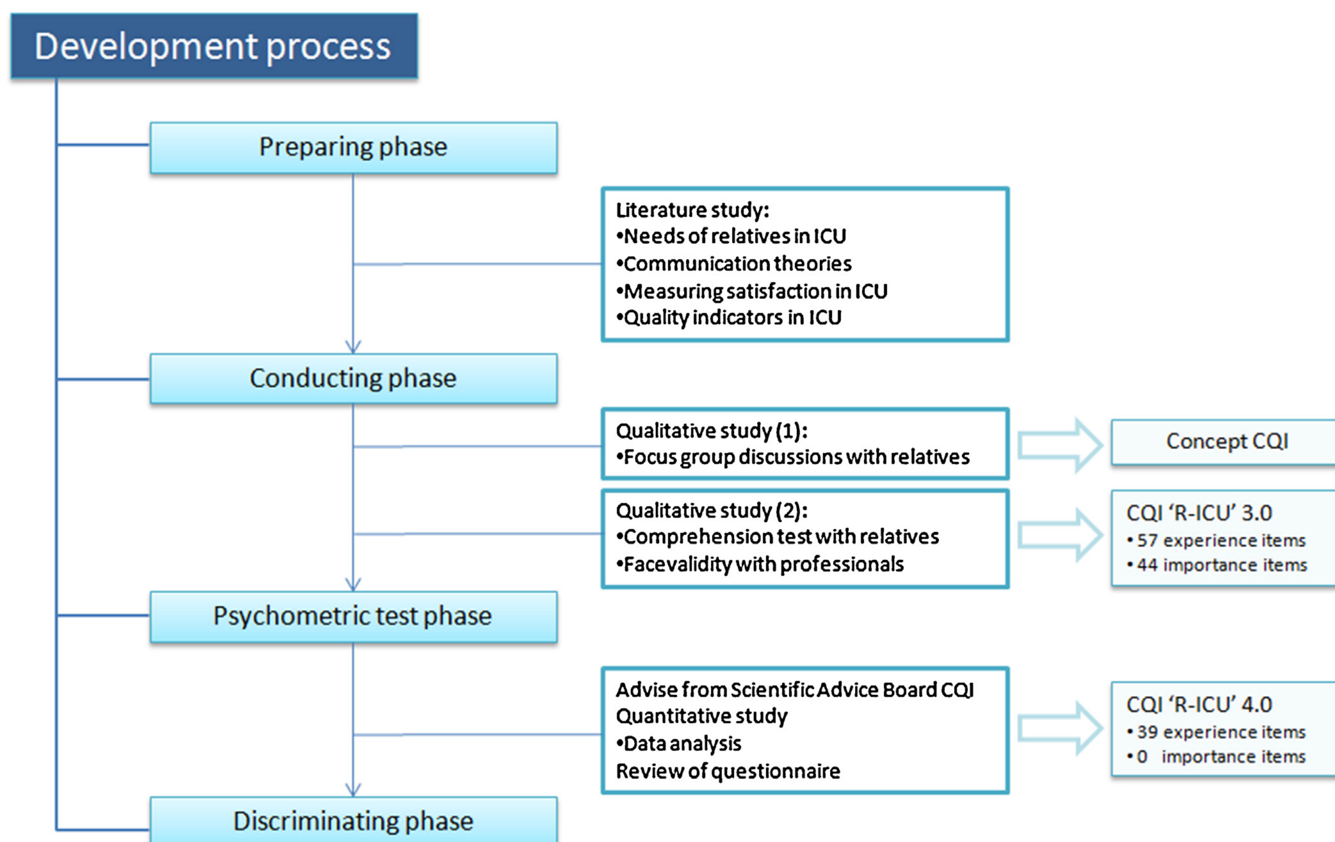

Fig. 1. Flow chart of the total development process which is carried out by the HAN University of Applied Sciences in order to meet the CQI method.

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