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Assessing the responsiveness of chronic disease care - Is the World Health Organization's concept of health system responsiveness applicable?

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ABSTRACT

The concept of health system responsiveness is an important dimension of health system performance assessment. Further efforts have been made in recent years to improve the analysis of responsiveness measurements, yet few studies have applied the responsiveness concept to the evaluation of specific health care delivery structures. The objective of this study was to test the World Health Organization's (WHO's) responsiveness concept for an application in the evaluation of chronic disease care. In September and October 2012 we conducted four focus groups of chronically ill people ($n = 38$) in Germany, in which participants discussed their experiences and expectations regarding health care. The data was analyzed deductively (on the basis of the WHO responsiveness concept) and inductively using directed content analysis. Ten themes related to health system responsiveness and one theme (*finances*) not directly related to health system responsiveness, but of high importance to the focus group participants, could be identified. Eight of the ten responsiveness themes are consistent with the WHO concept. Additionally, two new themes were identified: *trust* (consultation and treatment are not led by any motive other than the patients' wellbeing) and *coordination* (treatment involving different providers is coordinated and different actors communicate with each other). These findings indicate the suitability of the WHO responsiveness concept for the evaluation of chronic disease care. However, some amendments, in particular an extension of the concept to include the two domains *trust* and *coordination*, are necessary for a thorough assessment of the responsiveness of chronic disease care.

1. Background

The responsiveness of a health system is considered as one of three intrinsic goals of health systems (World Health Organization, 2000) and has been described as "a key characteristic of effective health systems" (Coulter and Jenkinson, 2005, p. 355). It is defined as a measure of how well a health system meets the non-medical, legitimate expectations of a population in its interactions with the health system (Darby et al., 2000).

The World Health Organization (WHO) developed the concept of health system responsiveness and its operationalization, based on an extensive literature review that draws from a variety of disciplines (De Silva, 2000). It is a concept focusing on patients' experiences during actual contact with the health care system and is, thus, less dependent on patients' expectations than, for example, patient satisfaction instruments (Busse et al., 2012). With the aim to measure responsiveness across countries, the WHO reduced the number of the concept's domains to a common set of eight, which are valid for all health systems (Valentine et al., 2003). These can further be categorized into two major domains:

(i) "respect-for-persons": consisting of the domains *dignity* (being treated with respect), *autonomy* (involvement in decision-making), *confidentiality* (personal data is kept confidential), and *communication* (the provider listens carefully and explains things clearly) and
(ii) "client-orientation": consisting of the domains *choice* (possibility to choose between different providers), *prompt attention* (getting fast care in emergencies, short waiting times), *quality of basic amenities* (cleanliness of the facility, seating, fresh air), and *social support* (access to social networks during inpatient care) (Valentine et al., 2008).

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The WHO responsiveness instrument was used, among others, within the Multi-country Survey Study on Health and Health System's Responsiveness (MCSS) 2000/2001 (Üstün et al., 2001) and the World Health Survey 2002 (Üstün et al., 2003) and its psychometric properties were tested using the MCSS and World Health Survey 2002 data (Valentine et al., 2007; Valentine et al., 2009). Further efforts have been made in recent years to improve the analysis of responsiveness measurements (Rice et al., 2011; Robone et al., 2011; Sirven et al., 2011). Nevertheless, most studies measuring responsiveness comprehensively focus on differences between countries (e.g. Sirven et al., 2011). Few studies have applied the responsiveness concept for the evaluation of specific health care delivery structures, such as delivery care, or specific subgroups of the population (Bramesfeld et al., 2007b; Liabsuetrakul et al., 2012). Hence, the applicability of responsiveness instruments to subfields of health systems remains hardly explored.

To our knowledge, the responsiveness concept has not been explicitly tested for an application in chronic disease care so far, except for the special case of mental health care (Bramesfeld et al., 2007b; Forouzan et al., 2011). For numerous reasons the appropriateness of the responsiveness concept for chronic disease care is highly relevant for a thorough assessment of health system performance:

First, assessing the responsiveness of a health care system without taking into account the specific needs of chronically ill people may lead to results that do not adequately reflect the health system's responsiveness for such patients. With the high and growing number of chronically ill people in the majority of countries (Busse et al., 2010), a high number of health care users would not be adequately included in the performance assessment. Second, the inclusion of chronically ill people in health systems performance assessment is of high value, as chronically ill people are considered to be extensive users of health care services and, therefore, to be experts in rating health care delivery structures (Blendon et al., 2003). And finally, although the responsiveness of a health system focuses on non-medical aspects of health, it is assumed to influence care-seeking behavior and compliance, creating improved, more open interactions between patients and their health care providers (Jones et al., 2011; Williams, 1994) which can be considered key factors in successful chronic disease care (Busse et al., 2010).

The objective of our study was to test the applicability of the core responsiveness domains defined by the WHO for the assessment of chronic disease care. We aimed to answer the following questions: Are the WHO responsiveness domains relevant for the chronically ill? Are further domains needed to provide a comprehensive measurement of the responsiveness of chronic disease care?

2. Data and method

We applied focus group methodology to gather information on patients' expectations regarding health services in general and to review the WHO responsiveness concept and its operationalization for chronic disease care within the German health care system. We decided to use focus groups because we were interested in what participants think and how they express their experiences and expectations regarding health care to one another. Focus groups have been reported to be suitable for research questions of this kind (Morgan, 1996). Additionally, focus groups have been used before and have proved appropriate to test and generate items for questionnaires (Barbour, 2005; Kirchberger et al., 2009; O'Brien, 1993).

For participation in the focus groups, we exclusively recruited chronically ill people. We did not differentiate between different chronic diseases or other factors (such as age, sex or disease severity) because we wanted to facilitate a broad discussion and we assumed the shared experience of chronic disease to be strong enough to achieve compatibility (Morgan and Scannell, 1998).

We started with recruiting participants for four focus groups, with the option to conduct additional focus groups if data saturation was not achieved. Ten persons were recruited for each group, using a multistage recruitment procedure. In the first stage, we advertised our focus groups using self-help groups for chronically ill people located in Berlin and a newspaper advertisement in a regional Berlin newspaper offering 25€ for participating. Secondly, interested persons who contacted us were asked screening questions. Thirdly, eligible persons (individuals who were chronically ill and who had sufficient knowledge of the German language) were invited to participate in one of the four focus groups.

The four focus groups were conducted in September and October 2012. All groups were conducted in the same facilities in Berlin and were moderated and co-moderated by the same two researchers. A manual was developed for the moderation. The discussion comprised four thematic sections divided into two parts split by a 20 min break (Fig. 1).

In the first part, participants were asked to talk about very positive and negative experiences they have had with their personal health care. In the second main part (after the break), the discussion was more focused: expectations were phrased based on the aforementioned experiences, clustered into categories and finally visualized by the moderator. When these categories were discussed, the moderator used the WHO wording that matched the responsiveness concept, i.e. expectations regarding waiting times were clustered into the category *prompt attention* (we applied the German translation according to the MCSS questionnaire (Üstün et al., 2001). Using the WHO wording had the advantage of examining whether the wording was intuitively understandable. When the participants told the moderator that the derived categories represent all of their personal health care related experiences, the moderator introduced any WHO responsiveness domain that had not yet been covered in the discussion by naming the respective keyword (e.g. *confidentiality*) and asking the participants if they had related experiences. At the end of the discussion every participant was asked to select the three categories they believed were the most important for their personal health care. All participants filled in a short socio-demographic questionnaire at the end of the focus groups.

The focus groups were audio-recorded and transcribed verbatim with the consent of the focus group participants. An assistant

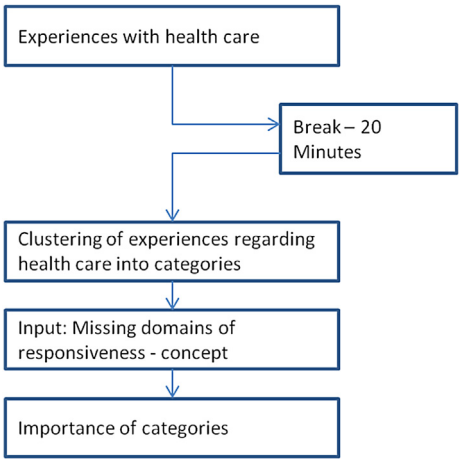

Fig. 1. Guideline for focus groups.