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Discussion

Strengthening patient and family engagement in healthcare – The New Haven Recommendations

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ABSTRACT

Objective: Present and discuss the development and basic structure of a multilevel approach to strengthen patient and family engaged care, “The New Haven Recommendations on partnering with patients, families and citizens to enhance performance and quality in health promoting hospitals and health services”.

Methods: A generic literature review was conducted followed by a Delphi procedure to prepare the New Haven Recommendations. From systems theory perspective, three conceptual levels are used to map action areas to enhance patient and family engaged care.

Results: The recommendations propose a multilevel approach to enable patient, family, (and citizen representatives’) involvement (a) within direct service provision; (b) among hospitals and health services; (c) in planning healthcare delivery systems and policy.

Conclusion: The New Haven Recommendations provide a strategic tool and practical recommendations, which can be used for reflection on current practices or generating new ways of thinking about patient and family engaged care. They support the development of patient and family engaged care as core aspect of high quality healthcare, and can contribute to achieving the Ottawa Charter’s claim of reorienting health services.

Practice implications: The potential benefit of the multilevel approach is to reorient the basic culture of healthcare towards patient- and health-centered care.

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1. Introduction

The World Health Organization (WHO) has played a decisive role in initiating and supporting partnerships with patients, families and citizens [1–4]. In 1986, WHO emphasized in its Ottawa Charter for Health Promotion [3] the relevance of reorienting health services towards health promotion and refocusing on the total needs of the individual. Building upon the Ottawa Charter, a feasibility study and first WHO-Model Project on health promotion in and by hospitals was conducted in the late 1980s in Austria [5] and, later, a European Health Promoting Pilot project followed [6].

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In 1990, WHO Regional Office for Europe (WHO/Euro) initiated the International Network of Health Promoting Hospitals and Health Services (HPH network) to support the development of health promotion in healthcare [7]. In these years, the HPH network developed a comprehensive approach to health promotion that aims to provide health promoting services for patients, staff and the regional population as well as organizational and quality development processes and structures. These processes and structures support health services to become a health promoting setting as a whole. In the last 25 years, the HPH network has become a significant international movement comprising almost 800 member organizations in 41 countries on all five continents. Since 2008, the network is an international association under Swiss law [8].

In 1991, the first policy paper of the HPH network emphasized that involving patients, families and citizens in health promoting healthcare is essential to enhancing healthcare and quality improvements. In particular, the Budapest Declaration on Health

Promoting Hospitals emphasized that hospitals and health services should “encourage an active and participatory role for patients according to their specific needs” [9].

Currently, widespread acceptance exists that health systems need to become more patient- and family-centered to meet the diverse needs of populations [10–12]. In this paper, we will outline how patient and family engaged care has gained increased recognition within the HPH network and how the network aims to improve it. “The New Haven Recommendations on partnering with patients, families and citizens to enhance performance and quality in health promoting hospitals and health services” (New Haven Recommendations) [13] represents the culmination of this development within the HPH network. It is presented as a multilevel approach with a broad spectrum of strategic options for change towards patient and family engaged care in healthcare. The multilevel approach originally comes from systems theory [14] and was adopted within the HPH network as a conceptual framework to distinguish three diverse implementation levels.

2. Patient and family engaged care in health promoting hospitals and health services

Following recommendations of WHO [2–4], the HPH network specifically focused on involving patients, families and citizens in health promoting healthcare from the outset. Citizens are also considered as potential future patients or family members. As mentioned earlier, the first HPH policy paper highlighted the active and participatory role of patients [9], other HPH policy papers followed [8,15–17]. To address the needs of specific target groups, HPH task forces have been developed with a focus on, children and adolescents [18], the elderly [19], migrants, refugees and minorities [20], and individuals with psychiatric and mental health challenges [21]. Outcomes are discussed during annual international HPH conferences [22]. However, a comprehensive strategy for systematically and sustainably involving patients, families and citizens in health promoting healthcare has been missing.

In 2016, the international HPH conference in the United States of America focused on patient and family involvement and was the main driver for the development of the New Haven Recommendations. Planetree International – the local host of the conference – is a pioneer in advancing patient and family engaged care. Since 1978, it has promoted the transformation of healthcare towards patient and family engaged care [23]. Other institutions in the US have embraced partnerships with patients as core to a national strategy and quality improvement agenda [12].

Family engaged care means that families (including significant others of all kind) are considered as important members of the care team and as an important source of both, information about, and assistance to, the patient. In some cultural contexts patients are always attended by their families and skillful consideration of their engagement is important for the wellbeing of the patients. This helps to provide individualized care to each patient and ensures the understanding and respect of each family's unique needs and preferences. In line with this, family involvement has been shown to improve the experience of the patient and contribute to better clinical outcomes [23,24].

3. Methods

For the New Haven Recommendations, a generic “literature review” following Grant et al. [25] was conducted. This aimed at investigating models of good practice and evidence-based interventions to strengthen patient and family engaged care. We limited our search for peer-reviewed papers in sociological, medical, psychological and nursing literature to the Web of Science. This results in limitation of the identified literature, but this review was

meant only to provide a sound foundation for the Delphi discussion. To explore how the HPH network has approached patient and family engaged care, policy papers, original, theoretical and conceptual articles of the HPH network were consulted. From the literature review, the main propositions of the New Haven Recommendations were described and a list of improvement measures was compiled as the basis for the Delphi procedure.

The Delphi procedure was applied to add to, complete and decide upon the main propositions of the New Haven Recommendations [26]. In two Delphi rounds, one expert of Planetree International, thirteen experts of the HPH network, two representatives of WHO/Euro, one policy expert, eight practitioners and researchers in the field, and two patient and family representatives (a) added relevant models of good practice and evidence from the literature, (b) specified actions to promote patient and family engaged care and (c) assigned them to the multiple priority levels (compare Table 1). These rounds were conducted via e-mail to permit efficient participation and feedback at each stage over a period of four months, from January to April 2016. A core team of three researchers and a practitioners in the field together with the expert of Planetree International integrated the feedbacks from the Delphi group at each round and conducted the final editing.

The final draft of the New Haven Recommendations was approved during the meeting by the General Assembly of the HPH network during the international HPH conference in the USA. In addition, all Delphi participants received the final draft after the conference via e-mail asking for some ultimate comments.

4. Results

The literature indicates that partnering with patients, families and citizens in healthcare can take many forms [27–29]. It varies between individual patient and family involvement, especially during direct service provision [30], and collective involvement on the organizational level and in planning healthcare delivery systems and policy [23,31,32]. The New Haven Recommendations consider patient and family engaged care in health promoting healthcare more broadly than simply what patients and families expect from the healthcare system. Following definitions by WHO, patient and family engaged care requires that patients' and families' needs and capabilities define (a) direct service provision (micro-level), (b) organizational structures and processes of hospitals and health services (meso-level), and (c) the regulations and planning of healthcare delivery systems and policy (macro-level) (see Fig. 1).

This approach expands the lens of patient and family engaged care beyond the individual and implies that interventions can take place on these three levels reinforcing each other. The New Haven Recommendations propose an array of evidence-/practice-based actions for each level (see Table 2).

a) enable patient and family involvement within direct service provision (micro-level):

On the micro-level, patient and family engaged care means that planning and delivery of healthcare consider each patient as a unique person with specific needs and capabilities. This implies considering the diverse needs of population groups (e.g. age, gender, cultural background, social status, language). Health professionals, patients and families jointly ensure that health (not only illness), and diverse goals, preferences, and values are considered and that an ongoing assessment of the match between the plan and process of care and patients' needs/concerns exists [33,34]. To implement this, the New Haven Recommendations suggest seven actions ranging from awareness raising and capacity-building among patients and families [35], shared-decision making, to the consideration of best

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