Patient perspectives on constrained patient participation in health care:  
A framework analysis

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ABSTRACT

Keywords— patient participation, person-centred care, qualitative research, framework analysis

INTRODUCTION

Patient participation (PP) is considered one of the ideals of contemporary health care. A recent critical analysis of person-centred PP in health care from patients’ perspectives showed that for such participation to be perceived as ideal, it needed to be based on patients’ experiences, values, preferences and needs in which respect and equality were central [1]. Such ideal person-centred PP manifested itself via three intertwined phases, presenting three core attributes. First the human connection phase which was divided into three main attributes: inviting atmosphere perceived; genuine attention felt and interest in patients and their conditions; being respected and recognised as equal human beings. Second the phase of information processing which was divided into the main attributes: seeking and receiving appropriate information; information-giving, dialogue and knowledge. Third, the action phase which was divided into the main attributes: confidence and accepting or delegating responsibility; shared decision making as desired; and perceived control over care. Yet the analysis also illuminated that not all PP is ideal. Non-ideal PP was according to patients characterised by communicational struggles between patients and HCPs, who did not allow the kind of participation the patients preferred. We have chosen to call such non-ideal PP ‘constrained PP’.

PURPOSE

To analyse critically attributes of the concepts ‘constrained PP in health care’; and ‘patient non-participation’ from patients’ perspectives though a review of qualitative research.

METHOD

Data were retrieved from data bases and analysed and synthesised according to an integrative review method and framework analysis. Sixty seven studies were included in the study. The diverse attributes of constrained PP were identified and contrasted and compared with; i) attributes of person-centred PP in health care already identified in an earlier study; and ii) attributes of patient non-participation in health care.

RESULTS

Constrained PP was not in accordance with patients’ preferences for participation and was characterised by lack of respect and unequal communication between patients and health care professionals. First, it manifested itself through the core attribute: having to fight for preferred participation which was divided into the main attributes: fighting to be seen and heard; fighting for receiving information; and fighting for being involved in decision making. The second core attribute
was being forced to participate more than preferred which was divided into the main attributes: being
forced to take responsibility; being forced to take decision; and being forced to comply and co-operate.
CONCLUSION
Conducting the present analysis from a person-centred framework yielded the novel result, not
documented in previous analyses, that not all PP is perceived as person-centred but can be
characterised by communicational struggles with HCPs who either do not allow patients as much
participation they prefer or force them into unwanted participation. Perhaps this lacuna in the
previous analyses can be traced to the fact that patients have not been asked direct questions that
could identify constrained PP, such as: ‘Have you participated less/more in your health care than you
would have preferred?’ In any case, the attributes of constrained PP identified above must be
regarded as a novelty in the literature. The illumination of constrained PP also raises the critical
question if HCPs, in some instances at least, are acting in accordance with the implicit paternalistic
assumption that it is in patients’ best interest that HCPs determine to what extent patients should
participate in their own care, regardless of the patients’ preferences and wishes for participation. A
paradox may lurk here: In order to satisfy the demands of anti-paternalism, some HCPs may see it as
their moral duty to, so to speak, ‘force patients to be free’. However, such a radical form of anti-
paternalism may itself wind up as being paternalistic and disrespectful.

REFERENCES
[1] K. Thórarinsdóttir and K. Kristjánsson, “Patients’ perspectives on person-centred participation in