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Review article

Patient autonomy in multiple sclerosis — Possible goals and assessment strategies

C. Heesen [a,h,*], S. Köpke [b], A. Solari [c], F. Geiger [d,e], J. Kasper [f,g]

[a] Institute of Neuroimmunology and Clinical MS Research (inims), University Medical Center Hamburg, Hamburg, Germany
[b] Nursing Research Group, Institute of Social Medicine, University of Lübeck, Lübeck, Germany
[c] Neuroepidemiology Unit, Foundation IRCCS Neurological Institute C. Besta, Milan, Italy
[d] Tumor Center, University Medical Center Schleswig-Holstein, Kiel, Germany
[e] Department of Pediatrics, University Medical Center Schleswig-Holstein, Kiel, Germany
[f] Department of Primary Medical Care, University Medical Center Hamburg, Hamburg, Germany
[g] Faculty of Mathematics, Informatics, Unit of Health Sciences and Education, University of Hamburg, Germany
[h] Department of Neurology, University Medical Center Center Hamburg, Hamburg, Germany

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ABSTRACT

Patient autonomy has been increasingly acknowledged as prerequisite for successful medical decision making in Western countries. In medical decisions with a need to involve a health professional, patient autonomy becomes apparent in the extent of patients' participation in the communication as described in the concept of shared decision making. Patient autonomy can be derived from different perspectives or goals and the focus of evaluation approaches may vary accordingly. Multiple sclerosis (MS) is a paradigmatic disease to study patient autonomy mainly because MS patients are highly disease competent and due to ambiguous evidence on many aspects of disease-related medical decision making.

This review gives an overview on measurement issues in studying decision making in MS, categorized according to prerequisites, process measures and outcomes of patient autonomy. As relevant prerequisites role preferences, risk attribution, risk tolerance, and risk knowledge are discussed. Regarding processes, we distinguish intra-psychic and interpersonal aspects. Intra-psychic processes are elucidated using the theory of planned behavior, which guided development of a 30-item scale to capture decisions about immunotherapy. Moreover, a theory of uncertainty management has been created resulting in the development of a corresponding measurement concept. Interpersonal processes evolving between physician and patient can be thoroughly analyzed from different perspectives by use of the newly developed comprehensive MAPPIN'SDM inventory. Concerning outcomes, besides health related outcomes, we discuss match of preferred roles during the decision encounters (preference match), decisional conflict as well as an application of the multidimensional measure of informed choice to decisions of MS patients.

These approaches provide an overview on patient-inherent and interpersonal factors and processes modulating medical decision making and health behavior in MS and beyond.

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* Corresponding author at: Institute of Neuroimmunology and Clinical MS Research (INiMS), University Medical Center Eppendorf, Martinistrasse 52, 20246 Hamburg, Germany. Tel.: +49 40 42803 2794; fax: +49 40 42803 6973.
E-mail address: heesen@uke.uni-hamburg.de (C. Heesen).

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1. Introduction

In a broader definition, patient autonomy (PA) in the medical context describes patients making use of their right of self-determination when dealing with a health matter. PA refers to patients' self-perception, perceptions by others as well as behavior in the fields of information seeking and perception, care, treatment, and medical decision making. Applied to the field of medical decision making, PA in Western countries is increasingly considered necessary. In medical decisions with a need to involve a health expert PA becomes apparent in the patients' participation in communication as described in the concept of shared decision making [1].

PA has been advocated for different reasons: First, for ethical reasons it is axiomatic to put every effort in supporting individuals' freedom of will as included in the guideline of the British General Medical Council (GMC) [2]. These guidelines also claim that there is a responsibility of patients to inform themselves before decisions are made.

Second, as making best use of scientific evidence for the individual patient is only possible when patient values are considered, PA is considered an essential part of evidence based medicine (EBM) [3]. In particular, patients' preferences should guide the choice, if the evidence does not clearly imply a first choice – which is called an equipoise condition – or even regularly if more than one option is available. Third, patients' autonomous participation in their health management might improve health outcomes due to a better fit of health decisions with individual needs. In fact, the evidence in this respect is ambiguous [4].

There are also possible misconceptions. In cases difficult to decide on, PA might be misused by health professionals as a possible strategy to avoid responsibility or as an efficient strategy to achieve higher compliance/adherence of patients who are given the impression of autonomy. Also PA might give the impression of the health system as a “health shopping center”, reducing health management and patient–physician relationship to an economic interaction.

All the more, most of these aspects are also relevant to the field of medical practice, training and research in multiple sclerosis. More and more partially effective costly treatments, some of them with considerable side-effects, are available [5]. So e.g. if to continue natalizumab treatment for more than two years when JC virus antibodies in serum are positive is a highly preference sensitive decision. Furthermore, recent studies have shown adherence rates of no more than 50% for first-line treatments [6]. The example of the recent discussion on venous "liberation" and the pressure of patient groups to gain access to this procedure also show possible misconceptions of PA [7]. Do these complexities call for more rigorous patient guidance especially in a disease which affects cognition and reasoning?

To account for this situation, the debate on the need for enhanced patient participation in this kind of complex medical decisions and on appropriate strategies to support patient autonomy should be held based on more clarity regarding the question for the goals of PA. Furthermore, the goals of PA should drive its evaluation: Is PA fulfilling an ethical postulate? Should it make the health system more efficient? Or result in better health outcomes?

It is unclear whether patient autonomy in treatment decisions should necessarily lead to an improvement of other “traditional” patient-relevant outcomes (e.g. mortality, morbidity, quality of life) or if involvement is a normative necessity and therefore a patient-important outcome on its own. An ethical justification of PA would therefore imply focusing the process of decision making. The evaluative focus lies in clarifying to what extent patients' decisions have been made autonomously, or to what extent patients were involved in their medical decisions. If PA is intended to act as a strategy to reach certain outcomes, any evaluation has to relate the extent of patient participation in the decision making process to these specific outcomes such as knowledge, compliance, realistic expectations, health status, disease management competences, or quality of life. Independent of the underpinning goal, PA needs evaluation regarding its basic, prerequisites and facilitating factors.

When our work on PA in MS was started in 2001, evidence was rare for general validity of instruments assessing doctor patient communication and efficacy of patient involvement interventions. As well, relevance of PA in MS had not been the subject of systematic research. Therefore, a considerable part of our work intended to yield a better understanding of the nature of medical decisions, communication processes, context and background. Furthermore, we conducted studies, where our evaluative approaches were applied in efficacy trials of interventions supporting MS-patients' medical decision making.

This review paper provides an overview of measurement issues and achievements at three defined time-points in a decision making process as has recently been proposed by Scholl et al. [8].

First we report on attempts to capture contexts, requirements or decision *prerequisites* building the ground upon which decision making processes unfold. Second we provide insight into approaches focusing the *process of medical decisions* including both, the internal (cognitive–emotional) and the communicative elaboration of a medical decision. Third, methods are described trying to differentiate medical decisions in terms of patient involvement on the level of *outcomes*. Outcomes can be defined on different complexity levels most simply as the distribution of choices or more complex in terms of psychological concepts as satisfaction and regret or even health state (Table 1).

2. Prerequisites

The specific process a person unfolds when facing a (medical) decision of pronounced importance is driven by a complex interaction of the person's cognitive styles, personality traits, cognitive and social competencies with the specific disease related and environmental context. These factors contribute to shaping of individual health belief models and coping styles. While unable to yield comprehensive assessment of all or even most of the factors which seemed relevant to us as prerequisites of decision making processes, we tried to identify possible markers with significant impact on these processes. Following many health belief models – such as e.g. the protection motivation model [9,10] – individual control beliefs and beliefs regarding self-efficacy are considered highly relevant for a given behavior. However, using the self-efficacy scale [11] and the health related locus of control [12] we hitherto failed in demonstrating the relevance of these traits for MS patients.

In addition, it is important how stochastic risks are attributed to individual cases (risk attribution) and to what extend individuals are willing to take risks when deciding on treatment options (risk tolerance). We have shown that patients experiencing natalizumab efficacy are willing to take a risk of up to 1:100 to get potentially lethal side effect (PML), which strongly exceeds what physicians would accept [13]. Although rational reasoning would imply equal risk to people in comparable situations, in fact people often tend to attribute their personal risk more optimistically or pessimistically [14]. In a study comparing methods to present numerical risk