

Patient participation in physical medicine and rehabilitation: a concept analysis

Abstract

Patient participation is crucial and has long traditions in physical medicine and rehabilitation. Despite that, there is a lacking coherent definition of patient participation in this context. By following the steps according to Walker and Avant a concept analysis of patient participation in rehabilitation has been conducted. Three attributes to patient participation in rehabilitation emerged: Active patient; Engagement and exchange from both the patient and the rehabilitation professionals; and Focus on the patient's condition, needs, desires and preference. If the attributes are fulfilled; the patient is treated as a capable person and will have greater motivation for being active throughout the rehabilitation. Further consequences of patient participation include improved physical functioning, coping, self-management and satisfaction with care. This study gives a suggestion for a common language in physical medicine and rehabilitation with regard to what patient participation conceptually means.

Keywords: patient involvement, goal-setting, shared decision-making

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Introduction

Patient participation is essential in physical medicine and rehabilitation.¹⁻⁴ The consensus about the importance of patients actively participating in their rehabilitation is unquestionable in the literature that refers to theories of rehabilitation, behavioral change and learning.⁵⁻⁹ In general, rehabilitation is primarily a process of education to improve the patient's physical, sensory, intellectual, psychological and social functioning¹⁰ to assist the patient in coping with his or her life situation with as little support as possible⁸ and to facilitate the learning process of how to live a life with a disability in one's own environment.⁹ An injury or disease requires a change in the patient's behavior and an adjustment to the new situation.⁹ Since a person acts for a reason, i.e. has a goal-directed behavior^{11,12} a crucial part of the rehabilitation is to implement interventions as meaningful and relevant for the patient.^{1,13}

The role of participating patients can be tracked back to 1950s.^{6,14,15} In 1955 Szasz and Hollender¹⁵ described different basic models of the physician-patient relationship. They related 'mutual participation' to rehabilitation, i.e. the patient's own experiences provide reliable and important clues for therapy and the treatment program itself is principally carried out by the patient.¹⁵ Hence, the patient should be considered as a person responsible for his or her own acts and behaviors.⁶ and without the patient participating in his or her rehabilitation, therapy can achieve little.^{1,14} In the past 20 years four concept analyses of patient participation have been published.¹⁶⁻¹⁹ Three of them have their origin in nursing,¹⁶⁻¹⁸ and one in a general hospital setting.¹⁹ Surprisingly, despite the long traditions and encouragement of patient participation in rehabilitation^{1-4,14,15} there are no concept analyses focusing on patient participation in a rehabilitation context. It has been showed that a closely related concept, person-centeredness, is used differently due to contexts and professions.²⁰⁻²² Therefore, it is likely that it also true for patient participation and a conceptual analysis is needed. By following the eight steps of content analysis according to Walker & Avant.²³ (Table 1) this paper aims to provide clarity in the use of the concept of patient

participation in physical medicine and rehabilitation by identifying and defining attributes, antecedents, consequences and empirical referents.

Table 1 The eight steps for a concept analysis according to Walker²³

Steps

- Select a concept
- Determine the aims of the analysis
- Identify uses of the concept
- Determine defining attributes
- Develop a model case
- Develop additional cases: borderline and contrary cases
- Identify antecedents and consequences
- Define empirical referents

General use of the concept patient participation

The concept "patient participation" is a two word construct. A "patient" refers to an individual or person receiving therapeutic, diagnostic, preventive or medical treatment in the health care system.^{24,25} Synonyms are "sick person", "case", "suffer", "victim", "invalid", "convalescent", "the sick", "the inform" or "valetudinarian".²⁵ "Client" is also a term for patient that can be used interchangeably.²⁴ Participation means literally "the action of taking part in something" and involvement, taking part, part, engagement, contribution, sharing, association, partaking and joining in are possible synonyms.²⁵ The International Classification of Functioning, Disability and Health (ICF) state that participation "is involvement in a life situation".²⁶ The ICF definition of participation refers to a number of activities a person can participate in²⁶ though not, related to participation in the role as patient.

As a Mesh-term, patient participation was introduced in 1978 and defined as “Patient involvement in the decision-making process in matters pertaining to health”.²⁴ Same definition of patient participation is provided in the Medical Dictionary Online.²⁷ The appearance of decision-making is also evident in the Free Dictionary by Farlex definition of patient participation: “A process in which both the patient and physician contribute to the medical decision-making process”.²⁸ Moreover, in the general concept analysis, Castro colleagues (19, p. 1929) define patient participation as “revolves around a patient’s right and opportunities to influence and engage in the decision making about his care through a dialogue attuned to his preferences, potential and a combination of his experimental and professional’s expert knowledge”. In the three previous concepts analysis stemming from nursing there are some commonalities about the attributes of patient participation, such as a relationship between the patient and nurse; a surrendering of power from the nurse to the patient; a sharing information and knowledge building; and an action phase with actively engagement.^{16–18}

Patient involvement, patient empowerment, patient activation or patient engagement are alternative entry terms to patient participation in MeSH.²⁴ The Free Dictionary by Farlex mean that patient participation can also be called shared decision-making.²⁸ In one of the previous concept analyses from nursing, Jo Cahill¹⁶ states that there is a hierarchical relationship, i.e. patient involvement/collaboration is a prerequisite for patient participation.¹⁶ Moreover, with patient empowerment in focus Fumagalli and colleagues²⁹ provide an analysis of several of those related terms to patient participation, including patient participation. In their concept mapping, patient participation and patient involvement is placed on the behavioral side whilst patient empowerment, patient activation, patient engagement and patient enablement are placed on the side of process and emergent state. Those sides are reciprocal connected in terms of both exploitation of motivation to increase patient participation and transferring motivation through the patient’s participation.²⁹ A linear relationship is in contrast to that, Castro and colleagues suggest.¹⁹ suggest that patient participation is a strategy that will facilitate a patient-centered approach, which in turn leads to patient empowerment. Likewise, Sahlsten and colleagues¹⁷ identified patient empowerment as a consequence from patient participation. Another contrast is, Thórarinsdóttir & Kristijánsen¹⁸ that do not make any differences between patient participation and consider concepts such as partnership, involvement, participation in decision-making and shared decision-making.

Specific use of the concept patient participation

In physical medicine and rehabilitation a diverse use of patient participation is evident. Some studies refer to patient participation as something objective, e.g. patients attending, being involved or take action in a specific program or intervention.^{30–37} The simplest way of classify participation is dichotomous, attendance compared to non-attendance.³⁰ Other studies do, however, provide degrees of patient participation.^{35–37} As suggestions for patient participation in goal-setting include: no participation; a little participation (i.e. asking the patient to give a broad goal for his or her rehabilitation); some participation (i.e. asking the patient to specify areas of activity performance they want to work on); or full participation (i.e. empowering the patients to actively choose goals and set time frames for them to be achieved).³⁵ Another way of classifying degrees of

patient participation and interaction with rehabilitation professionals (RP) in their rehabilitation planning is free choice level (i.e. the patient can answer four specified questions about his or her goals and goal attainment); multiple choice level (i.e. the RPs provide questions with three possible answers); forced choice level (i.e. the RPs provide a question and offer an answer); or no choice level (i.e. the RPs tells the patient what to do, and the patient may answer yes or no).³⁶ From an interview study about patients’ perceptions of their participation, three categories have been reported.³⁷ These categories are relinquishes (i.e. not interested in participating, easily accepts plans and decision supplied by the RPs); participants (i.e. shared decision-making and team discussions with the RPs); and occasional participants (i.e. restricted to participate due to RPs only occasionally asked for their participation).³⁷ Furthermore, other qualitative studies have suggested that the degree of active participation depends on the patient’s vitality.^{38,39} A patient may have little strength and energy in the initial phase after an injury.^{38,39} Further possible situations affecting patient participation are patient characteristics, such as being passive and dependent or controlling and independent, leading to different responses to participation.¹⁴ Some patients adapt a role they believe is a “good patient” characterized by passivity and compliance.⁴⁰ Nevertheless, participation gradually can take place.^{38,39,41} The RPs must increasingly facilitate active participation⁴² and the patient’s capacity to plan, decide and control.¹⁴

Other studies refer to the process of participation and its subjective meaning for the patients.^{38,39,43–45} Some examples are being in an exchange process;⁴³ a mutually shared process⁴⁴ and becoming in charge as soon as possible, but not until they felt ready.³⁸ The patient is present as an actor in all three examples and they all refer to the encounter between the patient and the RPs. With regard to the patients’ description of participation the encounter is most fruitful when RPs invite them to a dialogue.⁴³ Patients can experience that they participate in the encounter when they can respond to the suggestions made by the RPs and when they are asked for opinions.^{43,45,46} Moreover, patients feel that they participate when they are respected as unique persons^{39,43,45–47} and when their opportunities to participate are individually tailored.^{5,36,37,39}

In relation to patient participation there are two rehabilitation activities frequently used, namely goal planning and shared decision-making. Planning and setting goals is a well-developed and well-used strategy in rehabilitation, wherein the patient’s participation is non-arguable.^{6,11,34,39,48–53} (The patient should be active in defining his or her needs, what important goals and outcomes are, as well as priority and weight different outcomes.^{6,50,51} However, the patient needs help and coaching in this process.^{39,52} The patient has his or her subjective needs and wishes, while the RPs their clinical expertise.⁴ Goal setting is about negotiation and an agreement between the patient and the RPs is sought.^{4,11,49,53} Setting goals and priorities is a type of shared decision-making that occurs in rehabilitation.^{54,55} Mirjam Körner⁵⁵ refers to shared decision-making as an ideal model for the patient’s participation. This should be shaped by communication, cooperation, coordination and (working) climate between the patient and RPs.⁵⁶ A frequently used reference for shared decision-making originates in the patient-physician encounter.⁵⁷ Charles and colleagues⁵⁷ suggested that shared decision-making requires at least two participants (i.e. patient and RP/s) who share information, take steps to build a consensus about the preferred treatment and reach an agreement on the treatment to implement. Furthermore, there may be a hierarchy between decision-making and patient participation. Lawrence Schlesinger¹⁴

claims that allowing the patient to participate in decision-making will also make the patient partake more active in the rehabilitation process.

Patient participation is commonly addressed in the modern literature regarding person-centeredness. This is done either by considering patient participation and a person-centered approach as synonyms⁴⁷ or by considering patient participation as a prerequisite for and a vital part of person-centeredness.^{6,51} Specifically, Nordin and colleagues⁴⁷ claim that in practice, patient participation can be described by the Person-Centered Medicine model, i.e. patient participation is about understanding the patient as a whole person, acknowledging the patient's expertise, shared decision-making and developing a patient-professional relationship.^{58,59} The second, and probably most common way of looking at it, is that patient participation is considered as a vital component of person-centered care.^{6,51} For instance, Leplege and colleagues⁶ identified four conceptual pictures of the use of person-centeredness, one of them was Person-centeredness means that the person as an expert: Participation and empowerment. Another example is Cheryl Cott⁵¹ who found that Participation in goal setting and decision-making is one of seven components in client-centered rehabilitation.

Attributes to patient participation

As shown in the previous section there are different uses; therefore, the three attributes of patient participation in rehabilitation are a synthesis of the uses of patient participation in physical medicine and rehabilitation (Figure 1):

- i. Active patient. The patient should be the principal character in his or her rehabilitation. An underlying principle is that the patient is a subject legally responsible for his or her actions and wants to be in charge of his or her own rehabilitation. The patient may, although, not prefer or is not capable for an active role initially or in all situations. Hence, the RPs should be observant on the patient's abilities to increasingly facilitate his or her active participation.^{6,14,30,35,37,38, 43,45,46,50,51,57}
- ii. Engagement and exchange from both patient and RPs. In rehabilitation the collaboration and teamwork between the patient and RPs is crucial, e.g. during goal-setting, planning and therapy sessions. Both parts are seen as important contributors; patients with their subjective experiences and RPs with their medical and clinical competence, which they must share.^{4,11,37,39,43,44,49,51,53,55,57}
- iii. Focus on and respect for the patient's condition, needs, desires and preferences. The individual patient's situation – past, current and future – is the major concern within his or her rehabilitation. The focus is not only limited to the rehabilitation setting, it goes beyond the hospital walls and the patient is viewed as a person who should return to his or her life. It is the patient's rehabilitation; therefore, what is relevant and important for the patient serves as the basis for rehabilitation.^{5,6,36,39,43,45–47,50,51}

Figure 1. An illustration of antecedents, facilitators, attributes, consequences and empirical referents to patient participation in physical medicine and rehabilitation. The bullet points in each part are summaries of what has emerged from this concept analysis of patient participation in rehabilitation. The arrows show its relationship to one and another. It is a dashed arrow from facilitators to attributes as this was crucial in the rehabilitation literature, but facilitators are not originally a part of the concept analysis.

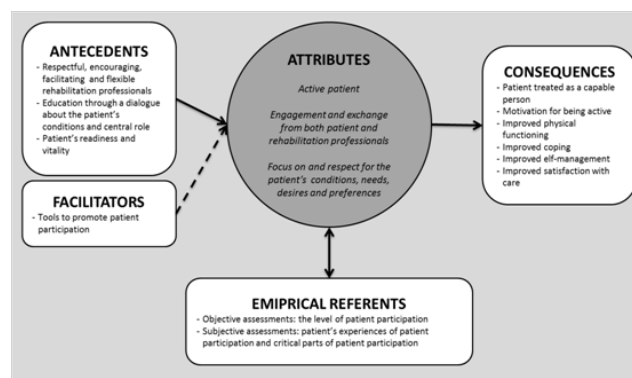


Figure 1 An illustration of antecedents, facilitators, attributes, consequences and empirical referents to patient participation in physical medicine and rehabilitation.

Model, borderline and contrary cases of patient participation

As illustrated below, patient participation in physical medicine and rehabilitation assume an active patient where there is an engagement and exchange from both the patient and the RPs and a focus on and respect for the patient's condition, needs, desires and preference. Peter is a patient at a spinal unit. He is suffering from a spinal cord injury after a traffic accident. When negotiating Peter's goals his experiences of his condition, needs, desires and preferences are the main focus. The RPs listen carefully to get to know Peter as a person and understand what the important and relevant aspects in his life are. The medical and clinical knowledge of the RPs is presented to Peter. The goals for the rehabilitation are jointly developed and serve as a basis for Peter's rehabilitation plan. The RPs encourage Peter to be an active participant in his rehabilitation, although, they take it step-by-step to accommodate to his readiness. As the rehabilitation proceeds Peter is taking on more responsibilities and agency in his rehabilitation. Though the process the RPs are sensitive to changes in Peter's condition as well as needs, desires and preferences. Peter's increased activity can happen because of the teamwork, including engagement and exchange from both Peter and the RPs.

A borderline case to patient participation in rehabilitation could be if the patient is active and there is an exchange between the patient and RPs, but what is most relevant for the patient is not addressed, for example. Sara is a patient at an orthopedic ward as she has recently gone through surgery for hip fracture. When the RPs meet Sara and ask for her goals they listen carefully. Sara is explicit in telling her wish to do gardening again. The RPs can present medical limitations that may prevent gardening after the hip fracture. It is followed by the RPs disregard for Sara's wish, rather than by suggested alternatives or potential other ways. The RPs encourage Sara to be active in her training and see her potential in taking own responsibilities. Sara is a compliant patient, tries her best to be active and learn from the RPs. Nevertheless, Sara seeks confirmation and asks for new goals related to her wish to do gardening. They can have a dialogue about it, but once again, it ends up in RPs not respecting and providing help toward achieving Sara's major concern.

In contrast to the attributes to patient participation in rehabilitation above, the patient as an active and capable part is neglected and the patient-RPs encounter consist of one-way communication where the

RPs stipulates the rehabilitation without considering the patient's wishes. Anna is 80 years old and has had a pulmonary infection. Anna's conditions are now stable and she has been admitted to a geriatric ward. When Anna meets the RPs they go straight forward and tell her about the plan for mobilization and the time of discharge. The RPs do not ask for Anna's opinions, since they know what the best is for Anna. The RPs do not take into account any ideas suggested by Anna though the rehabilitation, they just follow their pre-stipulated plan.

Antecedents and consequences of patient participation

The RPs as facilitators of patient participation is evident (Figure 1). They must be respectful for and listen to the patient's unique situation and conditions^{39,43,45,46} they must encourage and invite the patient to participate and proceed in his or her rehabilitation^{37,39,42} and they must be flexible and allow individually tailored rehabilitation.^{5,36,39,47} The RPs must also educate the patient about his or her condition^{39,43,54} as well as the rehabilitation process^{5,44,50,53,60} and the patient's role within it.⁶¹ All patients may, however, not be ready or understand his or her central role.^{38,39,43} and the patient needs to accept and adapt to this role before he or she can take an active part.^{40,44,61}

Different tools and working procedures to promote the patient's active role, in particular in setting his or her goals, are commonly used.⁶² Those cannot be classified as antecedent, rather it should be considered as facilitators. Some examples are The Goal Attainment Scale (GAS)⁶³ Patient Goal Priority Questionnaire (PGPQ).⁶⁴ The Patient Participation System.³⁶ The Canadian Occupational Performance Measure (COPM)⁶⁵ and The Needs Assessment Checklist (NAC).⁶⁶ In practice, such tools can be used to invite and encourage the patient to identify and describe his or her needs, preferences and goals. This can allow both shared discussions between the patient and RPs as well as set the focus on the patients past current and future situation.

Patient participation supports the overall goal with the rehabilitation, i.e. improvement in functions as well as facilitation the patient's everyday life benefit from patient participation. It has been argued that patients actively participating in therapy sessions are more attentive to instructions and receptive to feedback and also work harder.⁶⁷ Hence, they will get more out of their rehabilitation.⁶⁷ Objective assessments of the patient's participation are positively correlated to improved physical functioning.⁶⁶⁻⁷⁴ Likewise, interventions to increase the patient's participation are associated with better coping^{49,75} self-management.⁷⁶⁻⁷⁸ and satisfaction with care.^{49,75,79} A consequence evident in qualitative studies of patient participation is that the patient is treated as a whole person with dignity.^{39,43} This can be considered in line with the rehabilitative view of the patient as capable and responsible for his or her own acts and behaviors.^{1,6,14,80} Moreover, a patient who takes part in decision making¹⁴ or goal setting^{45,80} may have a greater motivation for actively participating in the whole rehabilitation process. Those consequences are summarized in Figure 1.

Empirical referents for patient participation

Both subjective and objective assessments are possible for determining patient participation in physical medicine and rehabilitation (Figure 1). Rettke and colleague⁸¹ report three different

instruments for measuring patient participation in rehabilitation: the Pittsburg Rehabilitation Participation Scale (PRPS);⁷² the Rehabilitation Therapy Engagement Scale (RTES).⁸² and the Hopkins Rehabilitation Engagement Rating Scale (HRERS).⁷¹ All these three instruments indicate that patient participation is about the degree of patient participation. Those are measurements of RPs' perceptions carried out by a single item for apprising the individual extent of participation;⁷² by multi-items that assess aspects such as the patient's attitudes, perceptions and expectations⁸² or by multi-items regarding the patient's therapy attendance, attitude toward rehabilitation and participating behavior.⁷¹

Another type of instrument is a self-assessment questionnaire from the patient's perspective, for instance the Patient Participation in Rehabilitation Questionnaire (PPRQ).⁸³ The PPRQ consists of five scales corresponding to central aspects of patient participation; Respect and integrity, Planning and decision-making, Information and knowledge, Motivation and encouragement, and Family involvement.⁸³ In contrast to objective assessments, with PPRQ patient participation is a subjective experience. Another self-assessment questionnaire is the Client Centered Rehabilitation Questionnaire (CCRQ) developed by Cott and colleagues.⁸⁴ The CCRQ has one sub-scale for assessment of Patient participation in decision-making and goal-setting (84). Moreover, the CCRQ also has a scale for educational aspects⁸⁴ which can be of importance in relation to the patient's participation.

Furthermore, Körner⁵⁵ suggests that The 9-item Shared Decision-Making Questionnaire (SDM-Q-9)⁸⁵ can be used for assessment of patient participation in rehabilitation. The SDM-Q-9 is a self-assessment questionnaire for evaluation of the patient's experiences of how shared-decision-making has been facilitated.⁸⁵ Likewise, general assessments of quality of care, such as The Picker Patient Experience Questionnaire (PPEQ)⁸⁶ also includes aspects related to the patients partaking in decisions and provision of information. Moreover, not specifically developed for rehabilitation, but for chronic conditions there are the self-assessment questionnaires The Patient Activation Measure (PAM)^{76,77} and The Patient Assessment of Chronic Illness Care (PACIC).⁸⁷ The PAM evaluates the patient's knowledge, skills and confidence for self-management.^{76,77} The PAM mainly focuses on the patient's abilities for managing his or her condition, but one item addresses the patient's active role in care and rehabilitation.^{76,77} The PACIC includes five sub-scales, and two of them, Patient activation and Goal-setting, relate to the patient's participation.⁸⁷

Study limitations

When interpreting the findings, with such an amount of literature written about rehabilitation there is obviously a risk to have overlooked some information that could have contributed to the analysis. This may especially be a problem since sources only written in English could be included. However, to minimize the risk of omitting valuable sources and obtain a picture as clear as possible of the use of patient participation, an attempt has been made to read and include literature from different sources, fields and professions. This analysis did not aim to distinguish patient participation between different professionals. Rather the intention was to provide clarity of what patient participation conceptually means within the wide spectrum of rehabilitation. There may, however, be certain diversifications in the patient-physician, patient-occupational therapist, patient-physiotherapist encounters etc. Furthermore, critique exists of the use of concept analysis it is seen as adapting to a reductionistic and positivistic stance.⁸⁸ However, Walker

and Avant²³ claim that concept analysis can increase the richness and clarity of a concept's use, which is important as concepts serve as critically bricks within theories. Moreover, to make use of a concept analysis it must be rigorously linked to the knowledge in a discipline.⁸⁹ In this case, the concept of patient participation in rehabilitation has long traditions and is an obvious part. But as shown in the section about its use, a coherent definition seems to be lacking.

Concluding remarks

As there seems to be a non-common language this conceptual analysis can give support to what patient participation conceptually means. In order to provide clarity in how the concept of patient participation in physical medicine and rehabilitation is used; it assumes an active patient, engagement and exchange from both the patient and the RPs, and focus on the patient's condition, needs, desires and preferences. The antecedents emerged from this concept analysis underpin the importance of RPs skills to promote actively participating patients. RPs must be empathic and respectful to the patient, provide information about both the patient's condition and the rehabilitation process, as well as allow the patient to participate according to their individual needs and in a flexible manner.

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Conflict of interest

The author declares no conflict of interest.

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