


SHORT REPORT

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Participation of adolescents with and without physical disabilities and chronic diseases: A comprehensive conceptualization

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Abstract

Background: In 2001, the International Classification of Functioning and Disability (ICF) introduced participation as a main goal of rehabilitation processes. However, to date, a comprehensive concept of participation in the rehabilitative context is missing, particularly in German-speaking countries. We thus aimed to refine and extend the existing concepts of participation in this brief communication.

Methods: In preceding studies, we conducted semi-structured interviews with adolescents who either had chronic diseases and/or physical disabilities or had no impairments and focus groups with parents and experts. Based on these diverse perspectives and findings, we refine the term *participation*.

Results: Participation is a construct that is embedded in a social context and consists of objective (i.e., attendance) and subjective (i.e., satisfaction and involvement) dimensions. These dimensions are reflected in different domains and areas that are relevant to adolescents' lives. In addition, the subjective relevance of respective areas in life needs to be regarded as a weighing component when evaluating participation.

Conclusion: Our results reflect international models on participation, refine the existing concept, and underline the multidimensional character of participation. These findings are urgently needed to develop appropriate instruments, for example, for assessing whether rehabilitative processes are effective regarding the goal of participation.

KEYWORDS

adolescents, disabilities, participation, rehabilitation

1 | INTRODUCTION

In Germany, the Federal Participation Act aims to strengthen the participation of people with disabilities in all areas of life (§1 SGB IX) and demands therefore appropriate instruments to assess individual

needs. In Germany, comprehensive participation self-assessment tools for adolescents are lacking (Gebhard & Fink, 2015). In order to develop such an instrument, it is necessary to refine the underlying concept of participation. In this paper, we sought thus to answer the following research question: How can adolescent participation be

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defined considering the perspective of adolescents, caregivers, and experts in the field of rehabilitation?

Within the International Classification of Functioning and Disability (ICF), participation is understood as “involvement in a life situation” (WHO - World Health Organisation, 2001). Although participation is defined as a goal of the rehabilitative process, the term *participation* is not clearly defined yet (Granlund, 2019) and remains thus imprecise in the context of rehabilitative context (Schuntermann, 2019). Recent research has moved away from the rather vague understanding of participation of the ICF. The most prominent concept on how to define participation was introduced by Imms and colleagues. They established the concept of the family of participation-related constructs (fPRC) (Imms, 2008). These constructs emphasize two main components of participation: attendance (objective component) and involvement (subjective component). Previous (qualitative) studies have also found that the subjective component is particularly important to adolescents (Hammel et al., 2008; Nyquist et al., 2020). Within the fPRC, the environmental context is also considered and thus broadens the understanding of participation. However, Imms and colleagues emphasized that neither component (attendance nor involvement) is yet fully understood (Imms et al., 2017) and the term *participation* remains thus rather vague.

To refine the concept, we assessed in preceding surveys the perspective of adolescents (Bärwalde et al., 2023) as well as the perspective of caretakers and experts in the field of rehabilitative context (Hoffmann et al., 2023). Instead of either a disability-specific or non-disability-specific approach, we aimed to gain a broad, generic, and comprehensive understanding of adolescent participation. Therefore, we assessed the perspective of adolescents with and without impaired health conditions and their caretakers (Bärwalde et al., 2023; Hoffmann et al., 2023). In this short paper, we sought to synthesize these qualitative results and, by doing so, refine the existing concepts of participation. The derived concept of adolescent participation shall be used as the foundation to develop a German self-rating instrument for adolescent participation.

2 | METHODS

The data on how adolescents, caregivers, and experts define the term *participation* come from our preceding qualitative surveys (Bärwalde et al., 2023; Hoffmann et al., 2023). Face-to-face semi-structured in-depth interviews were conducted with adolescents ($n = 14$ Adolescents with physical disabilities/chronic diseases; $n = 20$ Adolescents without physical disabilities/chronic diseases). To ensure intersubjective comprehensibility (Milford et al., 2017), multiple members of the research team then analyzed these interviews by applying grounded theory (Strauss & Corbin, 2010) to gain an in-depth understanding from the insider's perspective.

To gain a holistic understanding of adolescent participation, we assessed the caregivers' and experts' perspectives. Therefore, in-person focus groups with both the parents ($n = 5$ focus groups) and experts ($n = 3$ focus groups) were conducted. Content analyses

Key messages

- Participation is crucial for adolescent development, particularly for adolescents with physical disabilities and/or chronic diseases.
- So far, the understanding of how to define participation must be characterized as heterogeneous.
- Participation consists of an objective and subjective dimension. The objective dimension addresses the necessary but not sufficient prerequisite for partaking in divergent life situations and gives information about the *quantity*. The subjective dimension provides information regarding the *quality* of participation.
- To evaluate the level of participation in certain areas of life, it is important to put it into relation to how meaningful the area is to the individual. This can be done by assessing the subjective relevance of life areas and including it as a weighing component.

(Mayring, 2015) were used to analyze the focus groups of parents and experts, separately (Hoffmann et al., 2023). More information on methodological aspects can be found elsewhere (Bärwalde et al., 2023; Hoffmann et al., 2023).

2.1 | Triangulation of qualitative findings

Considering the different qualitative methods used, we applied a suitable design to triangulate the qualitative data (Carter et al., 2014; Flick, 2011). In a first step, we analyzed the data gained from semi-structured interviews with adolescents and focus groups with parents and experts separately. Thereafter, we put the results together by comparing the findings using applicable triangulation techniques (Carter et al., 2014; Flick, 2011). Method triangulation was conducted since two different methods, that is, semi-structured interviews and focus groups were used. As we assessed the perspective of diverse groups of interests and were thus confronted with multiple data sources, we also used data source triangulation. This was done to incorporate diverse perspectives on heterogeneous levels and to allow a comparison of the findings, and thus to gain knowledge about the concept of adolescent participation. By doing so, we clustered the diverse perspectives on participation, perceived determinants, and relevant areas of participation. Based on the triangulated findings, the research team derived the concept of adolescent participation that will be presented in the following.

3 | RESULTS

Considering that a detailed description of the qualitative findings was published elsewhere (Bärwalde et al., 2023; Hoffmann et al., 2023),

the diverse perspectives on the participation of adolescents, caregivers, and experts will only be presented briefly in the following, whereas the category system with example quotes can be obtained from Supplementary Material 1. The focus of this short communication lies on the derived concept of participation that was generated by synthesizing the separate findings.

3.1 | Adolescents' perception

From the adolescents' point of view, participation is primarily defined by the ability to interact with their social environment according to their individual expectations. Moreover, our findings emphasize the feeling of “belonging” as a central component of participation (see Supplementary Material 1).

3.2 | Parental perception

From the parental perspective, the focus is on the normative expectations of the majority of society and the wish that their children can partake in social life or rather participate in every area of life. Thereby, parents stress that their children should not be forced to adjust to fit in. Instead, social and environmental factors need to be changed in such a way that participation is possible for everyone despite their health impairments. In addition, parents are particularly concerned about the adolescents' well-being, which should be the superior aim of participation (see Supplementary Material 1).

3.3 | Experts' perception

Experts consider both the objective (e.g., formal integration in social groups) and subjective components (i.e., the feeling of involvement) as

being crucial for participation. However, the experts' focus lies on the subjective component of whether adolescents feel involved in every area of their lives. Moreover, experts expressed that the subjective perspective is crucial to meet their desire for participation (see Supplementary Material 1).

3.4 | Synthesized concept of participation

The derived concept of participation is displayed in Figure 1.

3.5 | Determinants of participation

Following our findings, participation results from several determining factors. Depending on the adolescents' subjective view, these determining factors can be perceived as being inhibiting, supporting, or not important. Although these factors determine participation, they are not strictly speaking part of the concept of participation, which is described in the following discussions.

3.6 | Dimensions of participation

In our preceding survey two dimensions of participation emerged:

1. the objective dimension, that is, attendance, and
2. the subjective dimension, that is, involvement and satisfaction.

The objective dimension contains attendance that can be described as partaking in social interactions addressing the adolescent functioning and the given opportunities. It is a necessary but not

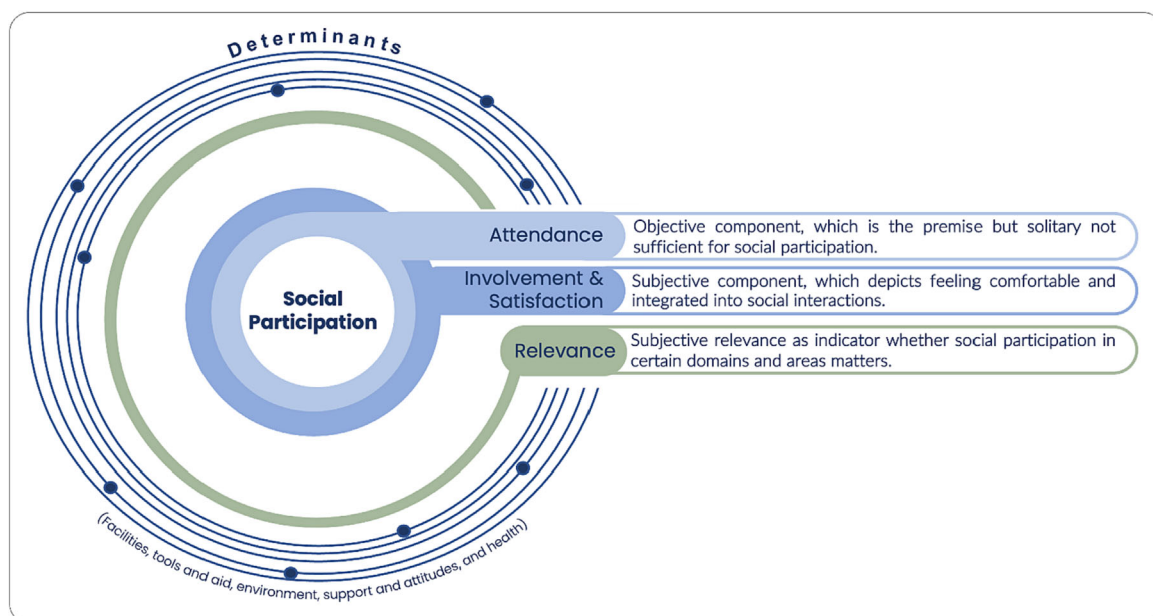


FIGURE 1 Conceptualized findings on participation and its determining factors.

sufficient prerequisite for participation. Particularly, caretakers emphasized how important these components are for adolescent participation. The objective dimension is complemented by the subjective dimension, which describes how integrated into social interactions someone feels (i.e., involvement) and how comfortable someone feels with social interactions (i.e., satisfaction). These components were stressed out by experts (see Supplementary Material 1, C1) and adolescents, who understand the term of participation as the feeling of belonging into social context (see Supplementary Material 1, A3).

3.7 | Subjective relevance

Moreover, as experts in this field emphasized (see Supplementary Material 1, C2), participation is very subjective and thus difficult to quantify. Therefore, we included in the concept of participation a subjective weighting component, that is, the subjective relevance. It rates how important the level of participation across divergent life domains and areas is to an individual. This follows the idea that areas that are rated to be more important to the individual require at least an equal level of participation. In turn, a lower level of participation is acceptable if the respective area is not evaluated as important.

3.8 | Social context of participation

As participation depends on social and environmental context, participation might vary across these divergent domains. We, therefore, synthesized our results regarding *where* adolescent participation takes place (Figure 2).

For adolescents, it can be distinguished between two domains, that is, general domain and school domain. Both domains address different areas of participation. The domain of school contains school-related areas, that is, (physical) education, school breaks, and trips. The general domain, on the other side, includes familiar interactions, friends, social media, leisure activities, and self-care.

4 | DISCUSSION

This article aimed to conceptualize our findings regarding adolescents' participation and thus refine existing concepts. Our synthesized results indicate, as requested before (Adair et al., 2015), that participation goes beyond the ICF framework.

The presented concept here comprises, on the one hand, the objective component of attendance that displays to what degree adolescents can partake in daily, school, and social activities. As family or more specifically parental factors, such as parental ethnicity, education, socioeconomic status, self-efficacy, and support, play an important role in their offspring's participation (Arakelyan et al., 2019), caregivers are to a great extent responsible to enable their children's participation. It is thus not surprising that the objective component was primarily emphasized by the parents. Their efforts, for example, meeting logistical challenges or providing a barrier-free environment, can be considered extremely straining (depending on their resources), a reason why they would need society to step up in order to disburden them.

Our results stress, however, that even though objective components are necessary for participation, subjective components are on the other hand particularly pivotal. The subjective dimension that includes involvement and satisfaction was pointed out by adolescents and experts and underlines the wish to interact with the respective social environment and gain a feeling of belonging. Involvement in areas in life that provided interactions with others was also found to be the central factor of social participation in other age groups, for example, older adults, participation (Levasseur et al., 2022).

As experts in the field stressed, participation depends on the subjective perceptions, wishes, and needs. Therefore, we included the subjective relevance regarding each life area as weighing factor. (Full) participation in certain areas might be considered dispensable if the individual ranks these areas as irrelevant. In turn, areas that are highly relevant for an individual require a sufficient level of participation. According to our findings, the subjective relevance is not a separate dimension of participation; however, it classifies the importance of participation for life domains and areas.

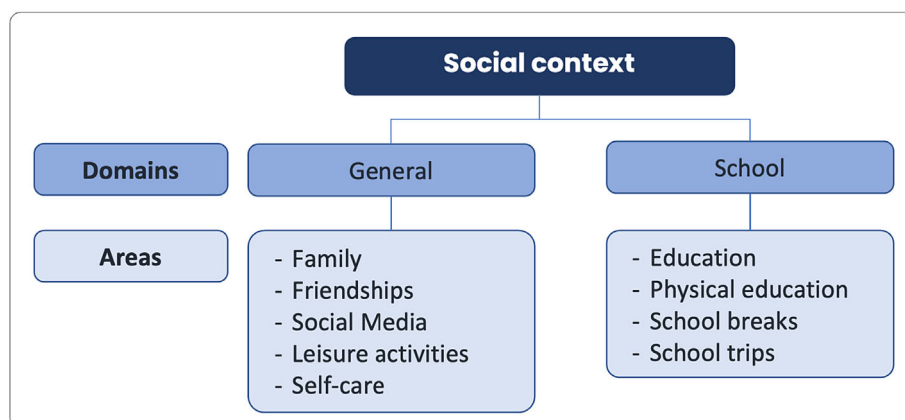


FIGURE 2 Social context of adolescent participation.

Our results are comparable with international findings. We found similarities with the model provided by Imms et al. (Imms, 2008; Imms et al., 2017), who carved out attendance and involvement as the main components of participation. This finding is in line with our conclusion. Unlike Imms and colleagues (Imms, 2008; Imms et al., 2017), we found how the wish for interaction and belonging (see Supplementary Material 1) sharpens the understanding of participation from the adolescents' perspective. By including satisfaction as an additional component of the subjective dimension, we address and emphasize these wishes. Furthermore, our findings on the concept of participation refine previous models by adding the respective subjective relevance as a central factor. Only an individual can decide which areas are important for his or her life and demand therefore (full) participation. This is particularly important to measure participation both accurately and subjectively based on individuals' wishes and needs.

Our findings underline the multidimensional concept that includes both objective and subjective components and the social context that extends far beyond the definition provided by the ICF. Our findings on participation can be used to develop instruments that are appropriate for measuring participation. Such instruments are needed to make participation as goal of rehabilitative processes verifiable and therefore fulfill the goal of the Federal Participation Act to strengthen the participation of people with disabilities in all areas of life (§1 SGB IX).

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

The study was approved by the Medical Ethics Review Board of the Medical Faculty at Martin Luther University Halle-Wittenberg (2017-67).

CONSENT TO PARTICIPATE

Informed consent was obtained from all individual participants included in the study.

AUTHOR CONTRIBUTIONS

Marie Bernard: Writing—original draft; conceptualization; investigation. **Laura Hoffmann:** Investigation; writing—review and editing; conceptualization. **Matthias Richter:** Project administration; supervision; writing—review and editing. **Carina Völlm:** Investigation; writing—review and editing; formal analysis. **Astrid Fink:** Funding acquisition; writing—review and editing. **Britta Dawal:** Conceptualization; funding acquisition; writing—review and editing; supervision; project administration.

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CONFLICT OF INTEREST STATEMENT

The authors declare that they have no competing interests.

DATA AVAILABILITY STATEMENT

The ethic vote does not allow sharing of the data.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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