Social consequences of unpredictable fluctuations in self-management interventions for young patients with chronic diseases: a rapid review

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Unpredictable fluctuations, episodic deteriorations, and flares are common in many pediatric chronic diseases. For many children and adolescents, their chronic disease is not a steady state of illness. On the contrary, a continuous ebb and flow of symptoms interferes with functional and social daily life. These fluctuations constitute a difficult challenge to patients' ability to self-manage their disease, fundamentally different from more predictable illness patterns.[1-3]

Numerous self-management interventions for young people with chronic conditions have been developed. do these self-management interventions offer young patients guidance on how to deal with the lack of understanding and even mistrust in school or at work, as a result of fluctuating disease activity?

In 2015, Sattoe et al. [4] performed an extensive search for papers on self-management interventions for 7 to 25-year-olds with somatic chronic conditions or physical disabilities. They distinguished three tasks involved in self-management: medical management (re. treatment), role management (re. social participation), and emotion or identity management (re. emotional consequences of being ill) [4]. The unpredictability of fluctuating symptoms substantially *affects role-management* in school or at work [1 3]. In 34 of the 86 studies (40%) included in the review, some form of role self-management was addressed [4].

Three reviewers (CS, DvV, SvG) independently assessed these 34 papers, to find clues on interventions dealing with social consequences of fluctuating disease activity in school or at work. One of the authors (DvV) emailed all researchers in order to increase sensitivity. We asked the authors to send us the manual or intervention description of their program. Furthermore, we asked them if they thought the theme of unpredictable fluctuations had been addressed in their intervention. Three reviewers (CS, DvV, SvG) independently assessed all received information. The findings were discussed and consensus was reached on potential disaccord.

We assessed the 34 papers in the Sattoe et al. review in which some form of role self-management had been mentioned [4]. In 30 papers (88.2%), the social consequences of unpredictable fluctuation were not mentioned at all. In four papers [5-8], we found some minor clues that it might have been a topic in the studied programs. We thoroughly assessed these papers and the underlying materials.

In the introduction of a paper on a school intervention for children with Sickle Cell, Koontz et al. stated: "The unpredictable, episodic nature of the disease can be especially disruptive to maintaining a normal schedule" [5]. However, in the description of the intervention, this theme was not addressed; the authors confirmed it was not part of the intervention. In a cognitive-behavioral program for adolescents with chronic pain, there was mention of the complex social and psychological problems associated with chronic pain, among which school absenteeism and nuisance in the

adolescents' lives [6]. Yet, the overview of the content of the program did not refer to unpredictability or fluctuations. In a web-based intervention for adolescent with type 1 diabetes, psychosocial demands such as struggling for identity, achieving independence and gaining peer acceptance were all mentioned as factors affecting compliance and school participation [7]. The author sent the method section of her PhD-thesis: the theme of unpredictable fluctuations was not specifically addressed. In the description of a camp for young people with end-stage renal disease, we found some potential clues that the topic of unpredictability might be addressed [8].However, the authors confirmed that the theme was not part of their manual. Still, in case the participants brought this theme up, it might have been discussed.

The authors of 16 papers (47%) responded to our inquiry. For 12 interventions, we received additional information, a manual or a protocol. In this extra information, there was no indication whatsoever that the programs dealt with the social consequences of unpredictable fluctuation of symptoms. None of the responding authors indicated that part of their intervention had been specifically aimed at this theme.

Based on this rapid review, we concluded that current self-management interventions for young patients with chronic diseases do not seem to target the social consequences of unpredictable fluctuations.

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