



A multicenter prospective quasi-experimental study on the impact of a transition-oriented generic patient education program on health service participation and quality of life in adolescents and young adults



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ABSTRACT

Objective: The aim of the study was to test the effects of a generic transition-oriented patient education program on adolescents' health service participation and quality of life (QoL).

Methods: We conducted a controlled trial comparing participants of 29 transition workshops with treatment as usual in 274 adolescents (16.8 mean age, SD = 1.76) diagnosed with type I diabetes (DM), cystic fibrosis (CF) or inflammatory bowel disease (IBD). A two-day transition workshop was carried out at 12 sites in Germany, focusing in standardized modules on adjustment to adult care settings, organization of future disease management, career choices and partnership. Study outcomes were health-related transition competence, self-efficacy, satisfaction with care, patient activation and QoL. Measures were assessed at baseline and six-month follow-up.

Results: Repeated-measurement covariance analysis using age as a covariate showed that the transition workshop significantly affected transition competence, self-efficacy and satisfaction with school care six months post intervention. The intervention did not significantly affect patient activation and QoL. However, post-hoc analysis suggested different effects across conditions.

Conclusion: The program has a positive effect on the competence of adolescents in the transition phase. **Practice implications:** The study demonstrates that an intervention can be effective in preparing adolescents with chronic conditions for transitions.

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1. Introduction

A patient education program, i.e. a standardized, manualized interactive group program, based on empowerment and self-efficacy, may be well suited for adolescents in the transition period [1]. There are condition-specific patient education programs that include aspects of transitional care, but low prevalence and variety of chronic conditions warrant a generic approach. A non-categorical or generic approach recognizes that many issues concerning psychosocial care share communalities [2]. All adolescents with chronic conditions have to cope with limitations with respect to social participation and functional capacity and must meet non-normative transition challenges [3]. The study group had developed a modular generic patient education program

from qualitative focus group and individual interviews with adolescents taking into account the views of affected adolescents as experts. Little is known about the specific needs of adolescents in transition and a lack of participation of the young people themselves may result in poor program planning [4–6]. The final program aims to strengthen the preparedness of young people to be responsible for and self-manage their own condition and is based on a framework of empowerment. We followed Zimmermann's conceptualization of empowerment containing an intra-personal component (one's capability to influence a given context), an interactional component (understanding how the system works) and a behavioral component (engaging in behaviors exerting control) [7]. More recently Bravo et al. [8] published a review of concepts of empowerment, describing five dimensions of empowerment: (1) self-efficacy, (2) knowledge, skills, attitudes and self-awareness to influence the own health behavior, (3) perceived personal control over health and health care, (4) sense of meaning and coherence about the condition, (5) health literacy and (6) feeling respected. Our intervention had a major focus on improving competencies and self-efficacy as well as behavioral

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changes such as self-activation. According to Fumagalli et al. [9] self-activation can be defined as “the acquisition of motivation (self-awareness and attitude through engagement) and ability (skills and knowledge through enablement) that patients might use to be involved or participate in decision-making, thus creating an opportunity for higher levels of power in their relationship with professionals” (p. 390).

We argued that a generic patient education program can be efficient because the psychological factors associated with the adaptation to the condition are similar and mostly independent of the diagnosis [10]. The modular approach supports the development of patient education programs for less common conditions [11] and was implemented by the German Network of Patient Education Programs for Children, Adolescents and Families (KomPas). The purpose of this study was to evaluate the effectiveness of a newly established generic patient education program for adolescents with a chronic condition during their transition to adult care and to quantify changes in health service participation and patient-reported outcomes. The process of transition from pediatric to adult services in adolescents with a chronic condition is seen as a challenging phase for adolescents, their parents and health professionals [12,13]. An unsuccessful transition can result in discontinuity and poor health outcomes [12]. Due to advances in medical care, increasing numbers of young people with severe and chronic conditions reach adulthood. Transition is defined as the cross-over point from pediatric medicine to adult medicine, including not only the real transfer from one physician to another but the whole process of an independent handling of the chronic condition when entering adulthood [14,15]. A successful transition is defined as the purposeful, planned movement of adolescents and young adults from child-centered to adult-oriented healthcare systems [14] and plays a crucial role in the ongoing engagement of the patient with the health-care system [12,13]. The transition from pediatric to adult care is often poorly managed [14]. A lack of follow-up care by a clinical specialist in adult medicine may result in discontinuity in treatment, and poor health outcomes [16–18]. There is increasing evidence that inadequate transition arrangements can have adverse effects on morbidity and mortality of young adults, mainly as a result of decreasing treatment adherence after leaving pediatric health-care [12,13,17]. In particular, studies showed a deterioration of disease parameters like the HbA1c in adolescents with diabetes [19] and inadequate self-management behavior [20,21]. Effective interventions at different levels are needed to improve the transition process because of the significant personal, social, and financial costs associated with this imperfect respectively interrupted care in chronic conditions. In parallel to the introduction of structural health service delivery concepts at the outpatient and inpatient level, as well as the improved integration between pediatric and adult medicine, a targeted support strategy

is required particularly at the individual health care level to prepare adolescents for the complex transition process [12]. In Germany, the reimbursement for the participation in a patient education program in an ambulatory setting is restricted to programs with evidence-based evaluation requiring controlled clinical trials. Only the programs for diabetes type I, asthma, atopic skin disease and obesity met the requirements and achieved general reimbursement policies by all insurers. Other smaller programs may be reimbursed as fee for service on an individual basis. Transition services are sporadically implemented as demonstration projects, for example as case-management projects [22,23] organizing the transfer or transition clinics [24]. No transition program in the format of an ambulatory patient education program in a group setting is currently available in Germany.

2. Methods

The study is a controlled trial comparing the effect of a patient education program in a group setting with treatment as usual in adolescents with chronic conditiontwo in transitional care with outcomes assessed at baseline, post-intervention and at six-month follow-up. The study was conducted in 12 pediatric outpatient clinics and rehabilitation centers in Germany. Ethical approval for the study was obtained by the University Medical Center of Greifswald.

2.1. Study design and participant recruitment

Adolescents were eligible for the study if they had been diagnosed with type 1 diabetes (DM), cystic fibrosis (CF) or inflammatory bowel disease (IBD) according to the International Classification of Diseases, 10th Edition (ICD-10), and were 15 years or older. These conditions were selected to represent varying health consequences [10], varying types of health service approaches towards transition and a varying amount of evidence concerning the effects of interventions in the transition phase. Exclusion criteria were being younger than 15 years, having a learning disability or insufficient German skills to participate in group discussions. Individuals were contacted and informed about the study by their physician in 12 clinical centers in Germany. The majority of centers were pediatric subspecialty clinics in tertiary care hospitals with outpatient departments; two were rehabilitation centers with in-patient services. In Germany, all children and adolescents have comprehensive health insurance coverage for acute in-patient and ambulatory care, and hospital-based rehabilitation services. Because no other patient education program for transition was available, the control group received care as usual including medical and rehabilitation care and counseling as needed, based on an individual needs approach. Power analysis

Table 1
Components of transition workshop curriculum [29].

Transition workshop modules	Subjects
Module 1: Let's go	Welcome, getting to know each other, subject overview
Module 2: Transfer to adult medicine	Differences & similarities between pediatric and adolescent medicine and adult medicine. Changes, risks and opportunities
Module 3: The new doctor-patient relationship	Considerations on change in doctor (qualification, preferences), role as patient
Module 4: Health insurance & related topics	Orientation within the health system
Module 5: Future & Employment	Employment/career aspirations, illness-related rights and obligations, training, study
Module 6a: People around me	Social support, conflicts with parents, dealing with parental worries, communication about illness in personal relationships
Module 6b: Doc special	Sexuality, alcohol, smoking and ill health
Module 7: My resources	Stress-management, sharing of illness related fears and concerns, realistic risk assessment, resource activation, methods in health management
Module 8: Close	Transfer in daily routine, planning of personal goals, exchange of experiences with an adult in similar/same situation, close

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