

Presentation at the 13th Research Conference of the Workgroup of European Nurse Researchers (WENR)

Chronic Illness Management, September 2 - 5, 2008, Vienna - Austria

Abstract:

IDENTIFYING ADOLESCENTS WITH CHRONIC DISORDERS AT RISK FOR SELF-MANAGEMENT FAILURE: CARE-RELATED PREFERENCE PROFILES AND THEIR DISTRIBUTION

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Aim

Adolescents with chronic disorders are seldom asked about their preferences for care, even though they are frequent healthcare users and are expected to take over responsibility for managing their own care. Aim of this study was to investigate preferences for self care and health care delivery in order to identify adolescents at risk for self-management failure.

Method

A web-survey among 984 adolescents (12-19 years, with various congenital and acquired disorders visiting Erasmus MC-Sophia Children's Hospital) and their parents (N=779) was done to estimate the distribution of four care-preference profiles, and to explore the associations with adolescent characteristics. Adolescents' fit to each profile was scored on a five-point Likert-scale. The four profiles ('Conscious & Compliant', 'Backseat Patient', 'Opinionated & Autonomous' and 'Worried & Insecure') were identified in a previous study using Q-methodology. Profiles' content differs in level of independence, self-management of the disease, adherence to therapeutic regime, and appreciation of parents' role. The wish to participate in treatment-related decisions is important to all profiles.

Results

Adolescents recognize themselves twice as often in the 'Conscious & Compliant' profile than in the other profiles. Fit to any of the profiles is associated with age, gender, quality of life, maturity, happiness, disability level, self-efficacy and readiness for transfer to adult care. The profiles signify potential risks for self-management failure. The 'Backseat Patient' and the 'Worried & Insecure' type feel less self-effective and may not be ready for the transfer to adult care, and the 'Opinionated & Autonomous' type is at risk for non-adherence. Parents assess their children fairly well, but underestimate their child's fit to the 'Opinionated & Autonomous' type.

Conclusions

The care-preference profiles are recognizable to adolescents, parents and nursing specialists, and they discriminate fairly well. Further use of these profiles by healthcare professionals to guide the transition to adult care will be explored.