

PARTICIPATORY RESEARCH: ADOLESCENTS WITH CHRONIC DISORDERS INTERVIEWING FELLOW PATIENTS ABOUT HEALTH CARE PREFERENCES

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Introduction

Children with chronic disorders are major users of paediatric services, yet they are rarely consulted as competent consumers. Even rarer is their active participation as co-researchers in studies.

Aim and methods

A participatory study was designed to explore experiences and preferences of adolescents with chronic disorders at Erasmus MC–Sophia, as part of a larger study of their competencies and health care preferences. Nursing specialists in chronic child care identified and invited nine chronically ill adolescents, aged 16–18, to act as co-researchers. These adolescents developed a structured interview protocol and received a short training to interview fellow patients. During a disco-party, that was organized in close collaboration with hospital staff, the co-researchers interviewed 25 fellow patients (12-19 years) and one another about care received in Erasmus MC-Sophia. Patients were invited for the disco party through leaflets distributed in the hospital by the nursing specialists. Free workshops were offered to the guests and a famous DJ contributed free of charge. Using comparative analysis, the senior researchers analysed 34 interviews. Subsequently, the co-researchers commented on preliminary results.

Results

The co-researchers were highly motivated to become involved in research. While designing the interview protocol, they had to make a selection from a wide choice of questions that emerged. Interviewing their fellow patients during the disco party was challenging and enjoyable to them. Due to their inexperience and to the disco setting itself, they did not manage to have in-depth conversations. The interviews, however, yielded many suggestions to improve care and communication with adolescents. The respondents appreciated being interviewed by fellow patients.

Conclusions

Adolescents are capable of participating as co-researchers and have valuable suggestions to improve care services and communication. Participation of adolescents in research also empowers them and supports their competency building. Further experiments with participatory health care research are recommended.

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