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**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 pediatric services, yet they are rarely consulted as competent consumers. Even rarer is their active participation as co-researchers in studies.

Aim and material

A participatory study was designed to explore the experiences and preferences of adolescents with chronic disorders at Erasmus MC–Sophia. This study was part of a larger study to investigate competencies and preferences of adolescents with chronic disorders. Nine adolescents, aged 16–18, developed a structured interview protocol and received a short training to interview fellow patients. During a disco party, organized for this purpose, they interviewed 25 fellow patients (12-19 years) and each other about care received in Erasmus MC-Sophia. Using comparative analysis, the researchers analyzed 34 interviews. Subsequently, the co-researchers commented on the preliminary results.

Results

The co-researchers were highly motivated to become involved in research. Designing the interview guide raised many questions and topics. Interviewing their fellow patients during the disco party was challenging and enjoyable to them. Due to their lack of training and to the disco setting itself, they did not manage to have in-depth conversations. However, the interviews yielded many concrete suggestions to improve care and communication with adolescents. All participants also appreciated being interviewed by fellow patients. Further experiments with participatory health care research are recommended.

Conclusions

Adolescents are highly 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.

Participatory research: *adolescents with chronic disorders interviewing fellow patients about health care preferences*

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SLIDE 2 research about adolescents growing up with chronic illness / physical disabilities

SLIDE 3 setting: the Sophia Children's hospital

Is part of Erasmus Medical Centre Rotterdam, the largest pediatric hospital in the Netherlands.

SLIDE 4 what is participatory research?

In participatory research, the research objects not only become subjects, but active partners (co-researchers). Their active participation is sought in as many aspects of the research as possible: continuous dialogue between young people and the researchers.

SLIDE 5 why participatory research?

Children should be seen as social actors, capable of reflexivity about their own situation
Child participation in decisions which affect them in everyday life is a fundamental citizens' right

Participation is appropriate from educational viewpoint: learning to take responsibility and to speak out

Giving adolescents a voice means taking them seriously. Good health care practice involves patients actively; the same applies to social research

SLIDE 7 research on your own feet

The aim of the study is to map preferences for health care delivery and competencies required to enable adolescents to independently direct their own treatment (self-management) and to function as an adult health care consumer. The research is funded by ZonMw - the Netherlands Organization for Health Research and Development.

Various qualitative research methodologies have been employed. The research was followed by a large quantitative study in which health preferences and competencies of adolescents with chronic disorders were explored. Over 1000 young patients (2-19 years) of Sophia Children's hospital participated, and the same questionnaire was also submitted by some 800 parents. Data is currently being analyzed.

SLIDE 8 setting up participatory research in On Your Own Feet

Co-researchers were sought through the active involvement of nursing specialists in Sophia Children's Hospital. They invited adolescents over 16 whom they thought would be interested in participating in the research. Interview training was offered at the office of a new daily newspaper aiming at young people in the Netherlands. The chief editor of this paper provided tips and ideas on how to interview. We practiced interviewing and discussed topics for inclusion in the interview protocol.

SLIDE 9 training of co-researchers

SLIDE 10 development of interview protocol

Questions were developed in 5 areas, see slide. Co-researchers added questions we have not envisaged, such as experiences with acute care and opinion about hospital clowns: 'cliniclowns'. While some liked the clowns and all thought they were enjoyable for young children, quite a few adolescents found them very irritating and did not wish to be entertained by them.

SLIDE 11 disco party

Fellow patients were interviewed during a disco party, organized in a rock temple in Rotterdam during a Saturday afternoon. Again, many parties offered their free collaboration, including a well known radio DJ, the discotheque, graffiti & break-dance artists.

Young people were invited through leaflets and posters distributed in the hospital. Again, nursing specialists were supportive. Some 50 adolescents attended the party. Due to short preparation time and the end of the May holidays, the number of participants was somewhat disappointing, but the event itself was a great success.

SLIDE 12 results

34 adolescents were interviewed.

The interviews yielded many concrete suggestions to improve care and make caregivers more sensitive towards the needs of adolescents. All interviewees think it is important to be asked about their own preferences and ideas about the care they receive.

SLIDE 13 priorities in preferences

The results of the interviews during the disco party were used in a large quantitative follow-up study. Over 1000 young patients filled in a questionnaire about their health preferences and competencies. Among other things, they were asked to prioritize 9 statements about improvements in the children's hospital.

CLICK

They could select 3 options. Number 1 (over half of all young people selected this option) is:

- 1) pay have more attention to the needs of older children
- 2) I want more contact with family and friends through internet when in hospital
- 3) less waiting time
- 4) more activities to meet fellow patients
- 5) more palatable food in the hospital
- 6) less discomfort when I need to be injected / when blood is drawn
- 7) more color in the hospital consultation rooms, uniforms
- 8) more visits of animals in the hospital
- 9) doctors and nurses should listen better to me (only 15% scored this!)

SLIDE 14 discussion

- adolescents are highly capable and motivated to act as co-researchers
- participation in research empowers patients
- supports adolescent competency-building
- meets with a lot of enthusiasm
- yields valuable suggestions to improve care and communication
- but participation is difficult to maintain

We would advise everyone who wants to improve care to include patients, however young, as much as possible in research and decision making.