


From Spectator to Principal Character: Adolescents with Chronic Conditions in Medical and Nursing Consultations

An Observational Study Conducted with Nurse Specialists as Co-Researchers


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methods: interviews with youth at home

- semi-structured interviews: youth were invited to elaborate on the last consultation they had in hospital
- questions with regard to their competencies and preferences with regard to consultations, the actual and preferred role of their parents
- thematic analysis of transcripts using Atlas.ti




observations in OPD: methods

- nurse specialists involved in recruitment and observations; member check
- informed consent obtained from youth, parents and healthcare providers
- **non-participative observations**
- short structured interview with youth before and after consultation
- digital recording of consultations
- structured observational forms
- data analysis: Atlas.ti (transcripts)




participants (observations)

- 10 observers (6 nurse specialists, 4 researchers)
- 39 consultations at 8 different OPD’s in Erasmus MC Sophia Children’s Hospital
- 30 youth involved: 21 boys / 9 girls
- age: mean 15.6 years (range 12-22 y)
- only 9 (30%) youth come on their own to the hospital consultation; in 70% of all consultations one or more parents are present all the time




observations in 8 outpatient clinics

specialty	Youth	Observations
Diabetes Mellitus	6	15
Hemophilia	1	1
Hiv/Aids	6	6
Infl. Bowel Diseases	3	3
Pulmonology	5	5
Neuromuscular disease	5	5
Nephrology	3	3
Metabolic diseases	1	1
Total	30	39



web-based survey

theme / topic	# questions
Self-efficacy during consultation	11
Own score for independence	1
Actual behavior during last OPD visit	7
Subjects discussed during consultation	5
Importance of these subjects	5



what are they talking about?

- **often:** 70%-90% of consultations: *medical issues, health complaints, adherence to treatment, explanations regarding therapy*
- **regularly:** about half of all consultations (40-60%): *complications, explanations about disease, coping with illness, independence of young person, school, sports, future plans*
- **rarely** (up to 15%): *sexuality & partner relations, risk behavior, transition of care, parent dependence*

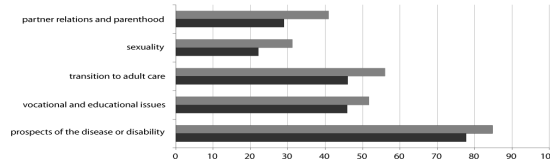


consultations: a medical happening

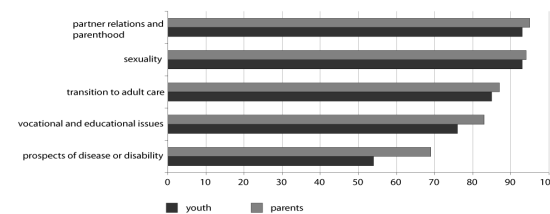
- consultations in the children's hospital are dominated by medical issues and concerns
- youth are not frequently asked for their opinion
- little attention is being paid to their own ideas and experiences in daily living with the illness
- risk behaviours and sensitive issues are rarely addressed
- few differences between medical - nursing consultations



Importance of sensitive issues during consultations (percentage answering 'very important' and 'important')



Frequency of discussion of sensitive issues during consultation (percentage answering 'never' and 'sometimes')



involvement and roles of youth during consultations

- youth come usually unprepared "*it's always the same*"; "*it's not necessary to prepare yourself*"
- youth seem involved, but are not very active during consultations
- observers rated half of all observed youth as *not active* or a *little bit active*
- more than half of youth took no initiative to ask questions
- leave the initiative to their parents



voice of adolescents: age matters (1)

Youth (12-15 years)

- take the role of spectator
- pose very few questions
- let their parents do the driving



"My mum says I should talk more, because I let her ask the questions"
Mustafa, 14 yrs, muscular dystrophy

"I always have to tell them how I feel. But I do not have any questions, usually. The consultations are actually more with my mother than with me, because I don't say much."
Sandra, 13 yrs, skin disease

voice of adolescents: age matters (2)

Youth (16-19 years)

- are more active during consultations
- *are capable* of acting as spokesman, but do not always *do so*
- usually play the secondary part, sometimes the principal part



"It is a bit strange, going on my own now, because I was always more of a bystander while my mother did the talking. Now I have to do it. But I quickly got used to it... Arjo, 17 yrs, metabolic disease

"I am the patient, you know. I am there for myself. So I want them to talk to me, I can answer for myself as I am 17. I open my mouth because I want to be informed about what involves me!" Maria, 17 yrs, BPD & scoliosis

roles of parents

- in 70% of observed consultations, parents are present all the time
- usually parents play an important, active part:
 - they report
 - they ask questions
 - they complement / correct
 - they sometimes dominate the conversation
 - arrange practical things
- the role of parents increases in the course of consultation as healthcare professionals shift their attention to parents



voice of adolescents: preferences for parents' role

- younger adolescents (12-15 yrs) refer to parents as "helping me", while older adolescents (16-19 yrs) say parents are "filling up the gaps" and "supporting me"
- sometimes they are uncomfortable with parents' presence, but usually they feel at ease

"When I don't understand those medical things, my dad helps. He usually pays good attention." Vince, 12 yrs, hemophilia

"On the one side it is nice that my mother is present because she knows more about me than I do. On the other side, I cannot say all I like, because I do not want my mum to know everything." Annika, 17yrs, endocrinal disease

My mother is everything for me, so I want her to be with me when I'm there. If I forget something then she fills up." Daphne, 19 yrs, CF



preferences for parents' roles

- parents are important for youth: they provide support, act as reminder
- many youth prefer their parents to be present during consultation
- but they want healthcare providers to focus primarily on them
- they prefer not to discuss personal issues in presence of parents



roles of healthcare providers

- take the lead and have the most important role during most consultations
- try hard to involve youth in the conversation: at the start of the consultation they are primarily focused on adolescents
- in the course of consultation, focus shifts to the parents
- healthcare providers are not aware of this
- no difference between nursing / medical consultations



voice of healthcare providers

- they are often frustrated with the passive role of youth
- some attribute this to puberty, others to overprotective parents, few to their own behaviour / role
- feel they lack adequate skills for communicating with teenagers

"It's almost impossible to have a normal conversation with them. That's just part of being a teenager, whether they are ill or not. Not much you can do about that". (...) "They only come to hospital because we tell them to. There is no single adolescent patient who comes because they feel the need for themselves."

Participants Focus Group

"Your own attitude makes a difference. It helps if you ask the questions the other way around: not 'how many doses did you fail' but 'how many times did you succeed'. It helps if you tell them that it's normal to be non-compliant at this age."

adolescents' preferences for healthcare providers

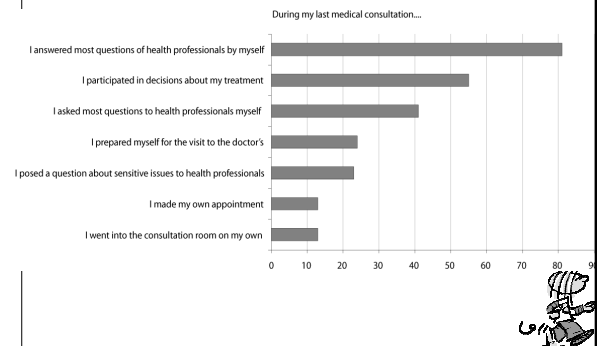
- healthcare providers should take adolescents seriously and not treat them in a childish way
- youth appreciate it when their opinion is asked and want to be listened to
- most do not mind it if healthcare providers confront them with the consequences of their behaviour



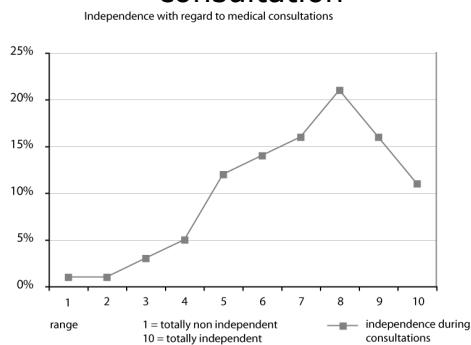
self-efficacy consultation



actual behaviour during last consultation



rating of own independence during consultation



a gap between feeling competent and acting independent

- many adolescents feel confident and think they are competent to participate in treatment-related decisions and in consultations
- still, in reality they hardly participate
- participation increases with age, but parents and healthcare providers set the scene and dominate the conversation
- adolescents often do not feel the need, nor are they stimulated



conclusions

youths' passivity is

- partly due to the predictable, routine character of the conversation and the dominance of the professional point of view
- being enabled and sometimes reinforced by the presence of their parents
- not challenged by healthcare providers

who should take the lead in change?



how to activate adolescents

1. let adolescents set the agenda
2. make sure that issues important to youth will be discussed
3. communicate directly with the young person
4. give adolescents concrete tasks in preparing the consultation
5. it is more important to listen than to talk to the adolescent
6. communicate in a youth friendly way
7. less routine consultations, experiment with consultation-on-demand
8. have adolescents also come alone, without parents
9. make sure that nursing consultations have their own unique content with a focus on psychosocial care
10. introduce group consultations



discussion

- methodological triangulation: useful to gain insight in process and motivations of various actors in the consultation
- observer triangulation: decreases reliability
- limited number of observed consultations: difficult to establish differences between medical and nursing consultations
- but nursing specialists were very positive about the experience of doing observations, were very involved and provided many ideas for change of their own practice



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