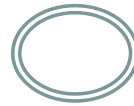


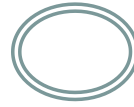
Transition



**A SIGNIFICANT PHASE IN THE
CARE OF THE CHRONICALLY ILL ADOLESCENT**

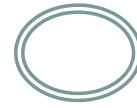
Anna Tornivuori MNSc, Childrens Hospital , Helsinki

Background



- In Western countries 20-30% of adolescents suffer from diseases which require long-term treatment and monitoring, and 10-13% of adolescents' illnesses significantly restrict everyday life, or require long treatment and follow-up periods (Yeo, Sawyer)
- The number of chronically ill adolescents is increasing constantly due to improved treatments (heart disease, cancer) and due to the increase of diseases (diabetes, IBD).
- Today, the vast majority of child and adolescent patients get to live to adulthood, and their treatment and follow-up moves from a children's hospital to adult units
- Mental health problems are more common amongst chronically ill adolescents than their peers.

Material and method

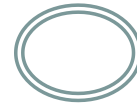


- A literary review of the concept of transition, an overview of the charter for adolescents' rights (NOBAB) and a thematic interview
- Interviewees were 18 year-old chronically ill adolescents that have been treated at the Helsinki Children's Hospital (immunology, diabetes, cardiology, internal medicine, transplant= 10 adolescents)
- Research during spring 2013
- Thematic interview topics: the adolescents' view on treatment received; readiness for transition, actual life situation

TRANSITION as a concept

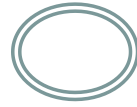


- "ALL TRANSITIONS ARE CHARACTERIZED BY FLOW AND MOVEMENT OVER TIME "
- "Internal processes usually accompany the process of transition while external processes tend to characterize change"



- **CONTINUITY**- Adolescents who because of their illness and/or functional disability need ongoing care have the right to continuity in healthcare service.
- **PREPARATION**- With good notice, adolescents have the right to actively participate in the preparation for the transfer to adult care.
- **INFORMATION**- Adolescents have the right to get information about the consequences of the transfer to adult care.
- **COOPERATION**- Adolescents have the right to actively participate in all decision-making concerning their transfer of care to adult units
- **RESPECT AND INTEGRITY** – Adolescents' integrity must be respected concerning the transfer of care to adult care.
- **QUALIFIED PERSONNEL**- Healthcare workers who take over treatment and care of adolescents must have the required education and qualifications to do so.

Caritative Caring Ethics



- to be present, to see, to witness, to bear responsibility

TRANSITION

respect and integrity

To be present, to understand the direction of the adolescents life

continuity

preparation

To bear responsibility
Humble encounters create confidential and individual treatment

THE ADOLESCENT

To see, to confirm the adolescents dignity by seeing, understanding and knowing

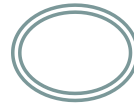
qualified personnel

cooperation

To witness, validating and identifying the adolescents' positive energy

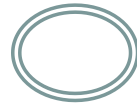
information

Results



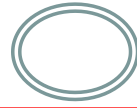
- Adolescents want to be met as a valuable individual, not as the stereotypical youth
- Health personnel need to have a true interest and a deep understanding of the adolescent's life situation
- Good care is holistic and includes the understanding of where the adolescent is coming from and where they are going
- Good care strengthens the adolescent's efforts to become independent and to take responsibility of their health and life.

....results.....



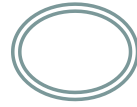
- The adolescents experienced joy and hope, these are strengths that the health personnel should take into account and support
- The adolescents want psychiatric support from their own health team. To visit a psychiatrist seemed strange and detached - psychological support needs to be integrated
- The task of the healthcare personnel is to support the adolescents' positivity

QUOTES



- The doctors can give advice and guidance , but I know myself best and in the end bear the responsibility
- It scares me the adult side, How will I get through it? I haven't been able to carry all the responsibility until now, how will it turn out when I'm even more alone? Will I only be one diagnosis amongst others?
- There should be a "sparkle in the eye", treatment should not be too serious. Health personnel need to be humane and understand adolescents.
- The adult side is prisonlike.....
- Psychiatric support needs to be included in my treatment and performed by familiar people. To go to a psychiatrist seems alienating

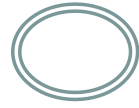
Quotes....



- The doctor treated me indifferently as a stereotypical youth: claimed I was tired and didn't feel well because I stay up all night by my computer and don't eat well! WELL-I don't even own a computer and I have been doing sports at a professional level all my life.....

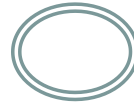


- "I'M AFRAID I WILL NOT BE HEARD AND THAT I WON'T BE TAKEN SERIOUSLY"



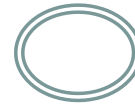
- "THE TRANSITION OF CARE IS A RESULT OF LIFE, OF GROWING UP. IT'S COOL TO GET MORE RESPONSIBILITY"

Section summary

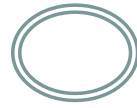


- Successful transition of care is a empowering experience. When the healthcare personnel succeed in supporting the adolescent through transition it makes a big difference for the individual, for their family, and for future care and costs.
- **YOUR ATTITUDE MAKES A DIFFERENCE**

PRACTICAL ACTIONS AT THE CHILDRENS' HOSPITAL IN HELSINKI

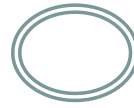


- A multidisciplinary transition team has been working since 2012 to promote the transition of care . The team has meetings three to four times a year,
- A generic model for the transition phase and an questionnaire for different patient groups have been created.
- CAMP days for adolescents with chronic illnesses,
 - Lectures, patient organization, group work, the adolescents form a support network through these activities
 - May 2015, Friday to Saturday, 30 adolescents 18 girls and 12 boys (different patient groups)
 - The adolescents that attended the Camp days felt ready for the transition and all the new challenges it may bring. The most valuable experience was the feeling of belonging and to get to know other adolescents in the same situation, especially reaching the understanding that adolescents with different diagnosis face the same kind of problems during transition of care
- Web pages and an individual electronic "passport" are still in progress



- As an example, the implementation of the transition model at the transplant unit of the childrens' hospital reduced the risk of graft loss and complications (F. Ortiz et al. 2015)

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