NON-ADHERENCE IN ADOLESCENT TRANSPLANT RECIPIENTS

IS PATIENT EDUCATION PRACTICE CONGRUENT WITH HEALTH-CARE PROVIDERS' BELIEFS ?

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(Non)-adherence from a patient's perpective…

It's all about limits… Being ill confronts you with your limits. Doctors keep telling you: "Don't do this, don't do that" (…).

However, when you manage somehow to do this or that (which is contrary to what you were prescribed), only then you realise that you don't belong to the Dead as they had already categorised you, but that you are still alive!" (a patient)

Non-adherence
(bio-psychosocial and educational perspective)

Unmodifiable risk factors

uch as personal medical, ocio-demograhic and istorical factors

Identification of patients « at risk »

Tailored individual follow-up

Modifiable risk factors

Personal (or family) cognitive & psychosocial Factors

Factors of interactio in particular with healthcare providers

Identification of general needs linked to the processes of learning self-care skills, adjusting psychosocially, and growing up healthily

Systematic patient education interventions

OBJECTIVE & HYPOTHESIS

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- **Objective:**
  - **To understand better how the healthcare providers (HCPs) in our programme address the issue of (non)-adherence with adolescent patients.**
- **Hypothesis:**
  - **HCPs' attitudes toward their educational role regarding (non)-adherence is influenced by their understanding of adolescent needs and possible meanings of (non)-adherent behaviours in this population.**

MATERIAL & METHODS

Study 1: exploratory qualitative study

- **Individual interviews, focus groups & observant participation**
- Aim: **generate hypotheses regarding healthcare providers' beliefs** on:
  - **Psychosocial impact of pediatric liver transplant**
  - **Attitudes toward non-adherent behaviours and meanings**
  - **One's own educational role**
- Period: nov. 2007-april 2008
- N=22
  - **14 nurses (63,6%), 6 doctors (27,3%), 2 other paramedical**

Study 2: descriptive quantitative study

- **Self-administered questionnaire**
- Aim: **further develop hypotheses generated by study 1**
- Period: nov. 2008-april 2009
- N'=31
  - **20 nurses (64,5%), 6 doctors (19,4%), 5 other (16,1 %)**
  - **Mean age: 38 yrs [24-56]**
  - **Mean time in the profession: 14 yrs [1,5-34]**
  - **Mean time pediatric liver transplantation : 14 yrs [1-24]**

Main RESULTS

BELIEFS REGARDING THE MEANING OF NON-ADHERENCE (NA)

tudy 1 (qualitative results)

There is a **GREAT VARIABILITY of POSSIBLE MEANINGS of NA**:

- NA is unavoidable during adolescence,
- NA is forgetting to take one's drugs,
- NA is linked to a lack of awareness regarding consequences of NA,
- NA is the expression of being fed-up,
- NA is the indicator of other underlying problems, such as complicated family history, sexual abuse, etc.

Study 2 (n=31)

- **PSYCHOSOCIAL DIFFICULTY LINKED TO CONDITION** (« FED UP »): 30/31
- **NORMAL DEVELOPMENTAL TASK**: 26/31 believe that NA is normal in adolescents, and that it is the indicator of a desire for greater autonomy
  - However, only 7/31 believe that it is an unavoidable phenomenon
- **LACK OF RESPONSIBILITY**: 24/31 associate NA with a lack of responsibility, but in the same time 22/31 believe that NA may be a voluntary experimentation
- **PSYCHOSOCIAL DIFFICULTIES UNRELATED TO CONDITION**: 21/31 consider it a possible cause of NA
- **COGNITIVE FUNCTION**: 19/31 believe that NA is linked to a lack of awareness of consequences

COMMON ATTITUDES TOWARD THE RISK OF NON-ADHERENCE

STUDY 1 (qualitative results)

NA is perceived as difficult to predict and detect… some HCPs experience feelings of powerlessness

- **PREVENTION** is done, using reminders which address the **cognitive & behavioural factors of NA.** HCPs try to be persuasive:
  - *Don't ever forget to take your drugs; don't ever forger that you depend on your treatment.*
- **AFTER NA IS DETECTED**: a sense of lack of self-efficacy was expressed
  - When *I detect NA, I write the information down, but I don't know what else to do »*
  - *I am often surprised… I didn't expect this particular patient to be non-adherent ; I did not detect the problem.*

PREFERRED ATTITUDES TOWARD THE RISK OF NON-ADHERENCE

RELEVANT:

- **NA should be accompanied:**
  30/30 (100%) agree
  Let's think together about what happened, so as to not let it happen again in the future.

- **NA sould be anticipated:**
  30/30 (100%) agree
  There will be moments in the future when you might find it hard to take your mediccation. It is important that we talk about your difficulties or errors if they happen

- **NA should be prevented:**
  28/30 (93%) agree
  Don't ever forget to take your medication!...

NOT RELEVANT:

- **NA should be fough against:**
  24/30 (80%) disagree
  You shouldn't have forgotten to take your medication. We'll have to be very strict in the future...

- **NA should be detected but canno be tackled:**
  28/30 (93%) disagree
  I know this patient forgets to take the drugs. I write it down but I do not know what else to d with this information and how t deal with it

RELEVANCE OF CONSIDERING DIFFERENT AREAS FOR PATIENT EDUCATION

Areas considered as relevant by all respondents (n=25)

- Technical information on transplantation & treatment
- Education to self-management of treatment
- Psychosocial counseling to parents and child in relation with acceptance of graft & life-long treatment

Areas considered as rather or potentially irrelevant

(response is either « not relevant » or « I don't know »)

- **Anticipe & facilitate transition from pediatric to adult-oriented care (11/25 question relevance)**
- **Explain liver transplant to peers at school (11/25)**
- **Explain how organ donation is organised (8/25)**
- **Explain to child, years after transplant, what disease caused the need for transplant (7/25)**
- **Address future health issues, such as future pregnancy-related issues (7/25)**
- **Facilitate process of transferring responsibilty from parent to adolescent regarding the management of treatment (5/25)**

DISCUSSION & CONCLUSION

DISCUSSION

Discrepancy between HCPs' beliefs regarding the meaning and factors of non-adherent behaviours, and the actual practice of patient education regarding long-term follow-up of pediatric liver transplant recipients:

Most HCPs believe that non-adherence should be considered a developmental task linked to a desire for autonomy, as well as a way of conveying that one is fed-up rather than the result of a lack of awareness regarding the consequences of non-adherence.

In practice however, most HCPs tackle non-adherence using reminders & warnings which address the cognitive and behavioural factors of non-adherence.

The relevance of patient education regarding the transition process which characterises adolescence is questioned by HCPs.

TAKE HOME MESSAGE

Current practice of patient education is influenced not only by HCPs' beliefs regarding the needs of patients who grow up with a liver transplant but also by HCPs' own sense of competence and efficacy regarding the long-term psychosocial follow-up of pediatric patients.

We recommend that exchanging on personal beliefs, values and goals be part of a multidisciplinary commitment toward promoting not only adherence, but also optimal psychosocial adaptation and personal development in adolescent transplant recipients.

Thank you!