To transplant or not to transplant: The case of B. a 17-year old Turkish girl with diabetes type 1 and CKD stage 5

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Case presentation – medical info

- 17 year old girl, intact family, 4 children, Turkish origine
- 2015: diabetes mellitus type 1
- 2016: chronic renal failure due to renal displasia, follow-up by specialized nurse for adherence problems
- November 2016: mother started screening process as living-related donor for pre-emptive kidney transplantation
- December 2016: intensive care, ketoacidosis, start HD, preparing for Tx

Psychological functioning

Individual factors:
- Low EF
- Puberty

Coping:
- Introvert about emotions
- Denial and avoidance of medical illness → Rejection of illness identity

Behavior:
- Low adherence
- High weight gain between dialysis sessions
- Lying

- postponement of transplantation

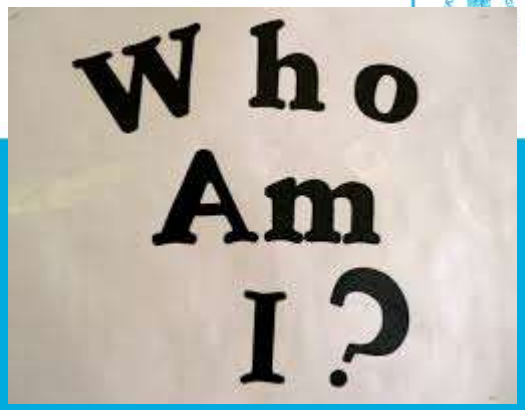
Feelings of anger, sadness, denial, resistance

Stressors:
- Serious medical problems (kidney, diabetes), deterioration and changes in short term
- Difficult combination school-illness

Family factors:
- Turkish family: influence of culture?
- Father dominant, mother anxious en low EF?
- Conflict between B and mother
- Few support in dealing with illness
- Impact of LD on the family dynamics?

Psychological functioning

- Strengths:
  - Social girl, happy, open in contact, friendly, many friends, loved by others
  - Humor
  - Can speak for herself
  - Family is involved
  - Perseverance in school



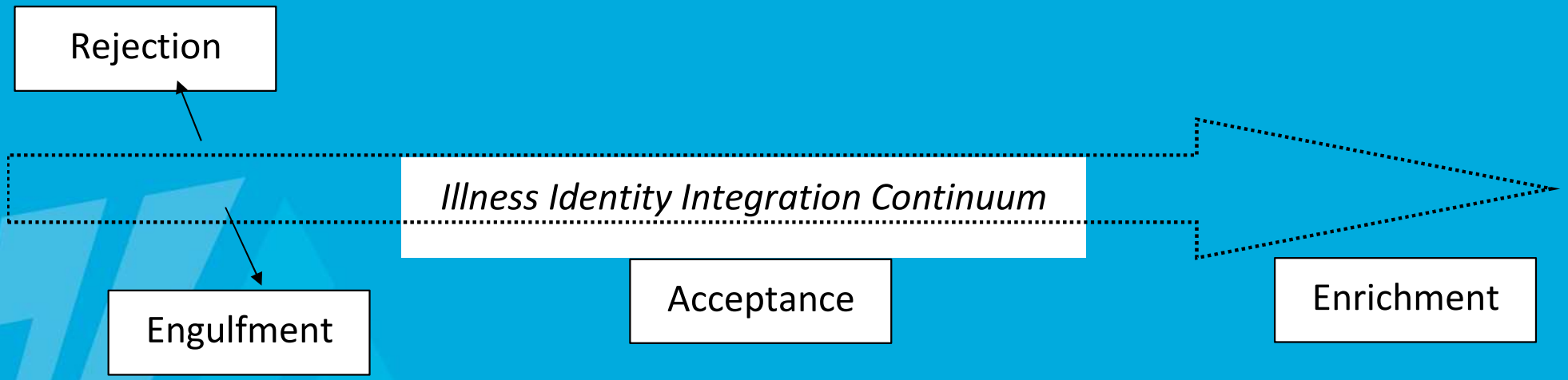
Concept of Illness Identity

- Adolescence: important changes at psychological, social and biological level
- Chronic illness: additional stressor!
- Adolescent with chronic illness has to cope with normative tasks (e.g. identity development) and non-normative tasks (e.g. integration of chronic illness in daily life)
- Why do some succeed, whereas other fail to adjust to chronic illness?

→ Concept of illness identity

Lugasi et al., 2013 J Clin Psychol Med Settings; Oris et al., 2016 Diabetes Care

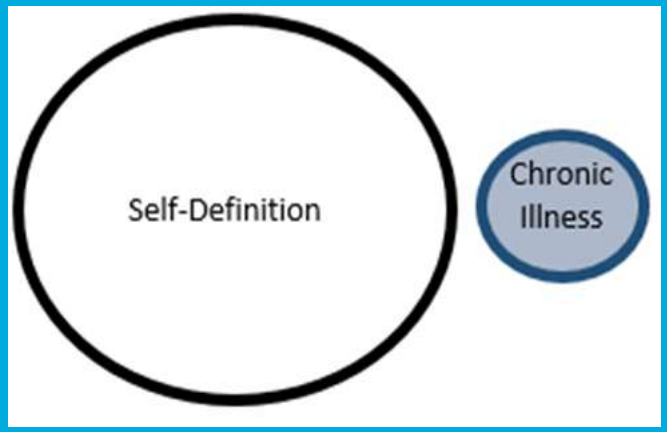
Illness identity – 4 identity dimensions



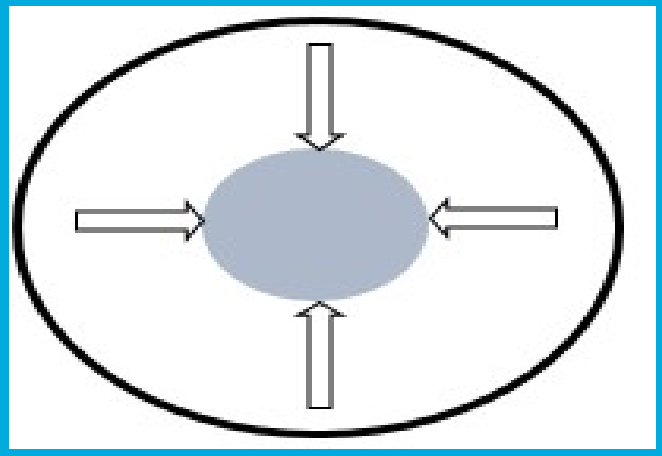
Drawing: Koen Luyckx, Katholieke Universiteit Leuven

Illness identity – 4 identity dimensions

- Rejection:
  - CI is rejected as part of one's identity
  - CI is unacceptable to the self



- Engulfment:
  - Individuals completely define themselves in terms of their CI
  - CI dominates person and life

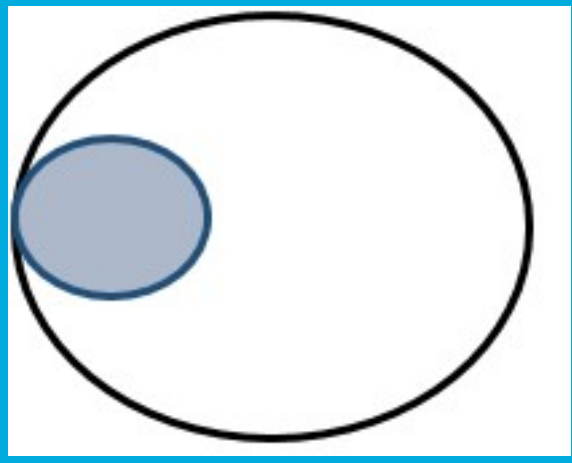


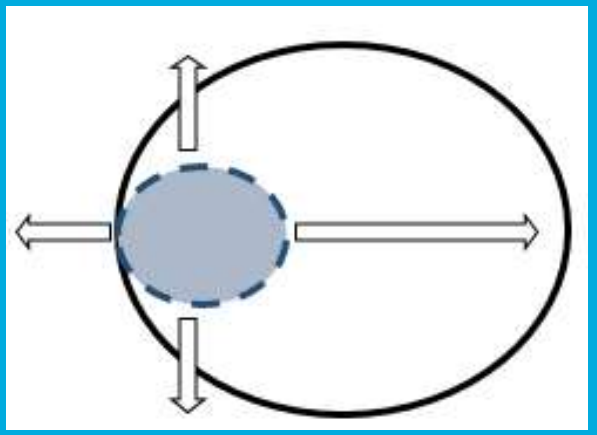
Drawings: Leen Oris, presentation 8/6/2015

Oris et al., 2016 Diabetes Care

Illness identity – 4 identity dimensions

- Acceptance:
  - Integration of CI in their identity without being overwhelmed or feeling reduced to a sick person
- Enrichment:
  - CI benefits their sense of self and enables them to grow as a person





Drawings: Leen Oris, presentation 8/6/2015

Oris et al., 2016 Diabetes Care

Illness Identity in Adolescents and Emerging Adults With Type 1 Diabetes: Introducing the Illness Identity Questionnaire

Leen Oris,[1] Jessica Rassart,[1] Sofie Prikken,[1] Margaux Verschueren,[1] Liesbet Goubert,[2] Philip Moons,[1,3] Cynthia A. Berg,[4] Ilse Weets,[5] and Koen Luyckx[1]

Diabetes Care 2016;39:757–763 | DOI: 10.2337/dc15-2559

- Oris et al., 2016:
  - Age and illness duration unrelated to illness identity
  - **Engulfment** → more depressive symptoms, more diabetes-related problems and lower satisfaction with life
  - **Rejection** lower treatment adherence and glycemic control
  - **Acceptance** → less depressive symptoms and diabetes-related problems, better satisfaction with life and treatment adherence
  - **Enrichment** → better satisfaction with life
- Development of Illness Identity Questionnaire: +1SD rejection, -1SD acceptance

Problems in preparing B. for Tx

- Difficulties in communication with B.:
  - Talks easy, however not about difficult theme's/illness, changes the subject, makes jokes
  - Has no own request for help
  - Ambivalent in communication, lying
  - Agrees to interventions, however does not comply when home

Problems in preparing B. for Tx

- Difficulties in communication with the family
- Cultural factors
- Language barriers

Problems in preparing B. for Tx

- Adherence problems:
  - Kidney:
    - Bad phosphate control – problems with fluid restriction
  - Diabetes:
    - Poor glycemic control
    - Bad adherence tot the diet and insulin therapy

→ March 2017: Tx was postponed

Psychological functioning

Individual factors:
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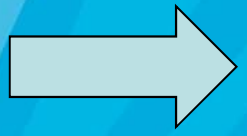
Psychological follow-up

- Individual factors:
  - Low EF: help in planning, organizing illness management by nurse, dietician
- Stressors:
  - School visit to talk about her illness to peers, promote support from teachers & peers, talk about combination school-treatment,….
- Coping:
  - Psycho-education about illness identity
  - Coping-skills training
  - Focus on wel-being, QoL, feelings

Psychological follow-up

- Family factors:
  - Try to improve support
  - Try to improve communication between B and parents
  - Try to motivate parents to help in the diabetes/illness management
  - ….
- Low adherence:
  - Motivational interviewing (but difficult)
  - Set individual goals for B. in collaboration with B (increase autonomy)



Very difficult to support her, to join with her, to implement the interventions,..

Individual goals for B.

Diabetes control:

- 4x/day glycemic control
- 4x/day insulin (3x Humalog® + 1x Lantus ®)
- registration
- 3 meals + 3 snacks

Phosphate control:

- 3x/day phosphate binder with meals
- low phosphate diet

Fluid restriction:

- max 800ml/day

Therapeutic plan in agreement with B.

- Week/weekend personalized schedule: nutrition, time of glycemic controls, medication

- Visual education material:

portions of carbohydrates and phosphate sources.

Therapeutic plan in agreement with B.

Glucose monitoring system: Freestyle Libre

- Glucose in the interstitial fluid
- Glucose when scanning + gives a trend ↑↓
- Changed every 14 days

Multi-disciplinary Education

- B.: 1x/week:

  diabetes nurse, dialysis nurse,
  dietician, psychologist and doctor

- Parents: goal 1x/2 weeks :

  education moments with interpreter and doctor,
  diabetes nurse, dialysis nurse, dietician, psychologist

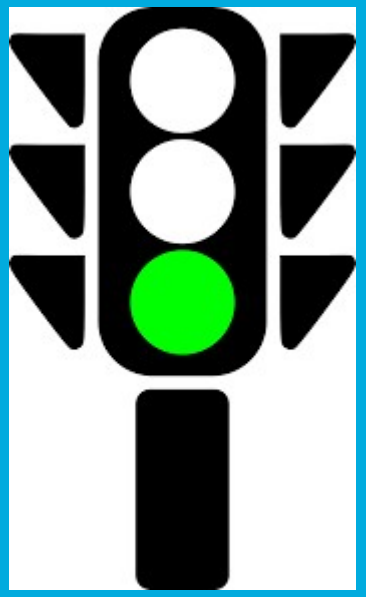
Follow-up after 2 months

- Improvement in:
  - Glycemic control due to sensor
  - Knowledge about disease, medication, diet
- However, still low adherence, difficulties in communication
- Advice: transference to Medical Pediatric Revalidation Center *Zeepreventorium De Haan*

Information of Revalidation center

- Easy social contact with other adolescents
- Good adherence during week:
  - Structure
  - Daily personal follow-up and support
- When home: difficulties in following structure, adherence problems continue

Discussion



- When do you think B. is prepared “good enough” for Tx? Which criteria should we take into account to assess this?
- What should we expect from the family? Should we expect more? Should we push more?
- Balance control vs letting go?
- When family Tx acceptable in this case?

Thank you for your attention!

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