Communication before and with chronic renal failure

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Leuven
Or: the challenges of medical communication in chronic disease
On psych-workers, consultations and liaison

**John's coffee-drinking**

<table>
<thead>
<tr>
<th>Event</th>
<th>Coffee Consumption</th>
</tr>
</thead>
<tbody>
<tr>
<td>John sees CRF children in his office</td>
<td>Decrease</td>
</tr>
<tr>
<td>John becomes part of the renal team</td>
<td>Increase</td>
</tr>
<tr>
<td>John becomes a liaison psychiatrist</td>
<td>Decrease</td>
</tr>
</tbody>
</table>

- Child Psych.
- Dialysis
Chronic renal failure (CRF) as a chronic condition

- [acute phase]
- Progressive renal failure
- Dialysis
- Kidney transplant
- Kidney survival & Immune suppression
A chronic condition over time

Symptoms, acute or more gradual and surreptitious
Diagnosis
Early treatment
Long term treatment
Evolution of the condition: improvement / stable / deterioration
# A chronic condition over time

<table>
<thead>
<tr>
<th>The medical facts</th>
<th>The subject’s perception</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptoms</td>
<td>Worries</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Relief + phases of grief</td>
</tr>
<tr>
<td>Early treatment</td>
<td>Relief, burden of treatment, expectations</td>
</tr>
<tr>
<td>Long term treatment</td>
<td>Burden, accommodation, seeking for alternatives, expectations,</td>
</tr>
<tr>
<td>Evolution</td>
<td>Adaptation to “new normal”</td>
</tr>
</tbody>
</table>
1. The archetype of medical communication:

The Doctor \[\leftrightarrow\] The adult patient

Overseeable & Stable
The medical communication process:

The Doctor

The Parent

The child
Communication in chronic disease

- Dietician
- Psychologist
- Pastor / Counselor
- All the other Doctors
- The Doctor
- Social worker
- The taxi driver

Complex & unstable

School
2. Everyone his/her own ideas...

- Let him not miss school
- Give her home tuition
- Long term school expectations should be limited
- Children with leukemia have normal school aptitudes
- Teach her English while she’s in sterile isolation
- It’s time for her (18 yrs) to find a boy-friend and live on her own
- She can stay with us forever.
And the benefits of the age of information

- Did you know drug-X has this side-effect?
- Abroad, it’s easier to get a kidney transplant
- XYZ-herbal tea is great for your glycemia
- Average survival of a kidney transplant is 7.2 years, so shouldn’t we put her back on Eurotransplant’s list by now?
- In hospital-Y they don’t advocate treatment-Z, so why do you doctor?

- This process is ongoing and generally goes far beyond the physicians imagination.
3. Medical communication in acute disease
Medical communication in chronic disease:

- Discussion & consensus
- And who knows what?
4. Great expectations thwarted?

- In chronic disease, patients tend to assume that treatment will be as curative as in acute disease.
- This will inevitably lead to disappointment.
- Only adequate information may reduce this effect.
- This requires an interactive information process, and addressing Care versus Cure.
5. The fallacy of normality and chronic conditions.

- Most quantitative psychological instruments assume there is a norm for adequate / happy / … functioning:
  - ± 2 SD
  - E.g. adaptive behaviour, school performance, intelligence, level of education, QoL-scales, job attainment, living independently vs. with parents…

- Normality is (implicitly) assumed as an end-stage goal.
- If the goal cannot be reached, non-normality is assumed.
- Non-normality is generally associated with unhappiness etc.

Foucault, 1970; Duffy et al. 2002

In a Foucauldian approach, happiness can only be
The non-normals often feel normal.

- Subjects with chronic conditions show this perception by others does not coincide with their own view
  - E.g. myotonic dystrophy, learning disability, adults & children in dialysis
- => Add qualitative research and assessment

Polaschek et al, 2003; Madden et al., 2002;
Conclusions: in chronic conditions

- The complexity of medical communication is of a higher order of magnitude
- Expectations are mostly based on an acute disease model
- Information evolves over time, is a process, not the sum of successive consultations, is interactive and multi-directional
- Our assumptions about psychological normality and quality of life should be reviewed

=> Physicians may rather need Johns to share the challenges in communication than to assess IQ’s and QoL in children with CRF
Thanks to Anita Devos

who has been the Leuven child renal team’s *John* for the past 17 years.