10 Living with End-Stage Renal Failure: A Developmental Task for the Adolescent

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Introduction

In this contribution a new approach will be described for studying living as a chronically ill person, or more specific, as an adolescent with end-stage renal failure (ESRF). The article is based on the assumption that it is important to know more about the psychosocial load on ESRF-patients. Furthermore, it is stated that the proposed model of developmental tasks can be used to approach all kinds of chronic illnesses and can be useful for adults and adolescents as well as for children.

The deficit centered approach to ESRF

Kidney-replacing therapies for children with an end-stage renal failure are relatively new. Since the seventies it has been possible to treat these children successfully. Therefore it is not surprising that the main concern so far has been with the medical implications of the various treatments. In the Netherlands the treatments available for children are hemodialysis, peritoneal dialysis and transplantation. Each kind of treatment has specific advantages and disadvantages and most children pass trough different treatments (Crittenden et al,. 1985).

Due to the experience with kidney replacing treatment of children, there is a substantial group of adolescents who has been living with ESRF since their youth. It has appeared that the therapies can be accompanied not only by medical problems but also by social and psychological problems. This insight resulted in a vast amount of articles summing up all kind of psychosocial problems adolescents with ESRF have to cope with. One may call this a 'deficit centered' approach in research.

The drawback of the deficit centered approach is the fixation on deficits, on the people who actually have problems with living as an ESRF patient. This fixation on problems caused a viewpoint in which these patients are experienced as deviant and psycho-pathological disturbed. According to Eiser (1990) this viewpoint is too limited. If one experiences people as deviant and even psycho-patho-

logical disturbed, it may be reasonable to conclude that only the expert (in this case the medical and psychological caretakers) knows 'what's best' for the patient.

This may be primarily the reason for the 'outsider's orientation' on the chronically ill, signalled by the medical sociologist Conrad (1987). He described outsider's orientation as "a view from outside the experience itself, minimizing or ignoring the subjective reality of the sufferer." In itself an outsiders view on the patients does not have to be negative. As said earlier, the deficit centered approach has laid hands on a vast amount of psychosocial problems that ESRF patients, and more specific ESRF adolescents, have to deal with (see Appendix 1). However, ignoring the subjective reality of the adolescents may lead to overlooking problems or to an incorrect pinpointing of problems. Moreover, the patients who did overcome their problems without seeking professional help, are seen as normal and therefore have been completely left out of consideration.

In conclusion it may be said that the deficit centered approach has not led to a theoretical frame, which can provide insight into the nature of the psychosocial problems. Furthermore, it has not given hints to the influence of these problems on adolescent development. Finally, this deficit centered approach will not produce knowledge about the development of the psychosocial problems itself.

Coping strategies

In health psychology it has become evidently promising to look at chronically ill as 'normal people in abnormal circumstances' (Eiser, 1990). In this approach the spotlight is on how to put up with problems, in other words: coping. Coping is described by Lazarus and Laurnier (1978) as "... the efforts, both action oriented and intra-psychic to manage (i.e. master, tolerate, reduce, minimize) environmental and internal demands and conflicts among them, which exceed a person's resources" (cited in Schaufeli & Dierendonck, 1992).

The adolescent ESRF-patients who did not need professional help in this view are considered as coping experts. If one can discover how these experts cope, it might be clear in which way people who did not find the correct coping strategies by themselves can be supported (Vlist & Eurlings-Bontekoe, 1992; Huygen & Sinnema, 1991; Eiser, 1990; Oldekinkel et al., 1992; Schaufeli & Dierendonck, 1992; Sanderman & Ormel, 1992). This view let opening to an 'insider's orientation', a directly and explicitly focusing on the subjective experience of living with and in spite of illness (Conrad, 1987). However, as holds for the outsider's orientation one has to avoid the pitfall of concentrating just on the problems even when these are described according to the patients' subjective experiences. If coping research stops when for every psychosocial problem the perfect coping strategy is found, the same mistake will be made as in the deficit centered approach. It will hardly produce knowledge about the development of the problems itself. And again it will not give insight in the influence of the psychosocial problems on ESRF adolescent development.

Developmental tasks in adolescence

In the above the focus is on the influence of living as an ESRF patient on adolescent development. An exposé about adolescent development may clarify this focus. Adolescence, mostly situated between age 12 and 20, is a transitional period between childhood and adulthood. Adolescents, like other people, develop expectations of what the major life-events and turning points will be, when they should occur, and how to react to them. In this period the sociocultural surrounding hands in a lot of norms and expectations. This includes achieving mature relationships with peers and forming sex-role identity, preparing for marriage and family life, achieving emotional independence of parents by finding a congenial social group, and preparing for an economic career, which includes planning education and finding an occupation. In other words: forming an identity. Relatively small decisions, such as who to date, whether to go to a certain college or to work, where and how to live, have identity-forming implications (Nurmi, 1993).

The transitions adolescents have to deal with can be described as 'developmental tasks'. The concept of 'developmental tasks' is used to refer to the episodes in which new competencies are formed. Heymans (1993) defined developmental task as referring to "a period or trajectory during which the individual has the opportunity to prove or make plausible before a specific audience or jury that it is capable to perform certain actions. This capability is inferred from the controlled and goal directed use of personal, social and/or material resources available. When the audience or jury is persuaded that the individual is capable, the individual is granted the right to act for his or her own account as if he or she has achieved the new competence."

Beside the perception of competence by the jury, the perception of the adolescent about his or her own competence is important. Harter (1990, cited in: Nurmi, 1993) suggested that the discrepancies between adolescent perceptions of competence (related to different developmental tasks) and the importance they attach to success in these domains, are highly correlated with global self-esteem. The sociocultural surrounding provides audiences (according to Heymans, 1993) that may influence this perception of competence, for instance in agreeing that the adolescent is capable to take care of its own diet. Moreover, the surrounding may provide resources that help to complete the task. Particularly parents and friends are such significant audiences and thereby may have impact on well-being.

Age related versus illness related developmental tasks

Adolescents confronted with ESRF have to overcome special barriers in fulfilling developmental tasks: life with kidney replacing therapies may disrupt the age related developmental tasks. Some tasks may be delayed, for example, the preparation for an economic career is hindered. Other tasks that normally belong later in the lifespan can be relevant at adolescence. For example, to deal with the possibility of a nearby death. The infrastructure may be disturbed by skipping tasks or by changing the order of appearance. Moreover, there may be developmental tasks generated specifically by living as an ESRF adolescent; the illness related developmental tasks. For example, to get used to depending on a dialysis machine to stay alive. In Appendix 1 psychosocial problems as highlighted in research literature are categorized according to the concept of developmental tasks. It attempts to relate to the signalled psychosocial problems each operating on a different level.

Illness related developmental tasks can disturb the age related developmental tasks. For instance, while getting used to a dialysis machine one's interest and energy for preparing a career could be very low. Age related tasks can also disturb illness related tasks. For instance, a social occasion like a dinner date can disturb the compliance to the special dialysis diet.

In these interactions the illness is seen as detrimental to the well-being of the adolescent. However, the interaction is not necessarily negative. The completion of an illness related task will give (as Heymans, 1993 puts it) "maturity, psychosocial health, and well-being" needed to fulfil age related developmental tasks and vice versa. According to the above mentioned, the perception of the completion of a developmental task depends highly on the self-articulated goals of the adolescent (Nurmi, 1993) and on the sociocultural surrounding in function of audience (Heymans, 1993).

In addition, the perception by the adolescent may be influenced by the individual cognitive style and strategies, such as optimism, defensive pessimism and self-handicapping (Nurmi, 1993). This lifestyle may be part of the theory a person constructs about how to interpret his or her experiences and what to do about it (Harré, 1989).

In particular, ESRF adolescents are looking for the meaning of being ill and this meaning correlates with how one experiences life (Heymans, 1993). The search for meaning and the construction of a theory about why one is ill, is reported frequently in (auto)biographic material of chronically ill people (Lefebvre et al., 1972; Vlist-Eurlings & Bontekoe, 1992; Conrad, 1987). The (momentarily) personal theory coincides, for instance, with the question of guilt, with denial or coping, and with types of help and support one asks for dealing with developmental tasks (Heymans, 1993). A construction of a personal theory may

even result in a so called reconstruction of the self (Conrad, 1987; Heymans, 1990; Charmaz, 1987; Nijhoff, 1991).

In sum it may be said that the concept of developmental tasks could be valuable for describing the ESRF adolescent development. It goes beyond the coping strategy and the deficit centered approach, without neglecting the benefits of these approaches. It provides a tool to link sociocultural influences and inter-individual comparison with intra-individual changes. Psychosocial problems are interpreted in context of the perceived goals and developmental tasks. Therefore, the content and development of the psychosocial problems itself can be spotted, as well as the influence on the development of the adolescent.

Research recommendations

The model of developmental tasks implies a specific methodological approach.

Firstly, to detect and study a period or trajectory of development a longitudinal design is necessary. A cross-sectional design, although less time-consuming, is not appropriate to follow the processes that occur within individuals over time. The longitudinal design should be corrected for cohort effects (cohort= group of persons born at the same time who may therefore share experiences that are different from those of older or younger persons) (Cole and Cole, 1989).

Secondly, the selection of subjects should concentrate on the type of life-events, instead of whether or not problematic reactions on these life-events occur.

Thirdly, to discover the experiences with life-events, as perceived by the subjects, a throughout and exhaustive data acquisition per subject is preferable, even if this implies restrictions on the number of subjects. Information has to be obtained about, in particular, the factual life-events, the experienced developmental tasks, the coping strategies, and the emotions that accompany the events and tasks.

Finally, the large appeal on the willingness of the subjects to co-operate in this extensive data acquisition implies a voluntary and motivated participation. Therefore, the data acquisition has to be attractive for the subjects.

The above can be translated to research on ESRF-adolescents. The first requirement, the longitudinal design corrected for cohort effects, may be approached by following adolescents of each age group among 12 and 20 years for at least thirty months.

The second requirement, selecting on type of life-events is more complicated. It is obvious to depart from the three types of kidney-replacing treatments, hemo-dialysis, peritoneal dialysis and transplantation, as three major categories of life-events. However, because of unpredictable changes in medical course, due to common occurring exchanges between therapies, it is not useful to form different groups of patients according to current treatment (Crittenden, et al., 1985). For subject selection the broader category of ESRF patients should be used.

Notwithstanding this entanglement of therapies during medical course, therapy type is an important variable vis à vis life-events.

The third requirement is an exhaustive data acquisition. A checklist may be used monthly to collect all kinds of illness-related and universal life-events. This checklist may be complemented by spontaneous diary reports. All experiences may be ordered every six months into developmental tasks by a 'course of life'-matrix. The columns of the matrix contain fields of development, for instance, medical careers, social contacts and school career. These fields can be defined in co-operation with the subjects. The rows of the matrix contain the periods of changes or stages the subject detects, related to years of age. The subject can fill in the cells of the matrix, with information about certain fields in certain periods. (Cruts, 1993). Coping strategies may be checked monthly by the 'Utrecht Coping List' (Sanderman, 1992). A checklist of hundred emotions may be used as a daily 'thermometer' to detect the emotions that accompany the events and tasks (Heymans, 1992). By combining the data of all these instruments with an intensive interview every six months, a pattern will be drawn of the processes that occur within each individual over time. To obtain a more throughout pattern, all these methods can also be used to study the parent's view on the development of the ESRF adolescents.

The forth requirement is about the attractiveness of the data acquisition according to the subjects. To avoid weariness because of frequent inquiries the variety of tests makes a welcome change. Moreover, it is important to interest the subjects in the aim of the project. Therefore, the subjects should be approached as experts on their own living with ESRF, or, for the parents, on living with a child with ESRF. It should be underlined that their willingness to share their experiences makes a fundamental support for ESRF adolescents conceivable. The fact that the 'Nierpatiënten vereniging LVD' (the Dutch organization of ESRF patients) founded a committee 'young ESRF patients' to stimulate psychosocial research, indicates an interest on the aim of the project. In addition, the subjects may repeatedly renew voluntarily the participation on the project. Experience with this kind of research indicates that the voluntary participation and the lack of pressure preserves the motivation (Heymans, 1992).

In conclusion, by following the research recommendations as stated above, it is possible to describe the development of ESRF adolescent by using the concept of developmental tasks.

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Appendix 1: contents part A to F and contains an overview of psychosocial problems that were found as a consequence of living with ESRF. The concept Developmental Task occurred to be very useful in categorization of this material. Future research might fill in empty cells. The categorization is not used in the literature (referred to by italic numbers). Therefore the author has full responsibility of the categorization in terms of developmental tasks.

A: The onset of the disease:		
Factors as indicators of:		
A frequent recurring event as a consequence of ESRF	**Disruption of age related developmental tasks**	**Newly generated illness related developmental tasks**
Pre dialysis *3, 14, 20* →	Is a progressive process *20*	The diagnosis is yet not to make; it is not clear what is wrong with the body *3* Painful medical examinations *14, 20* Seeking help and asking for information *3*
Making the diagnosis ESRF *3, 12, 14, 20, 24* →	#	Is a shock in spite of all examinations in advance *14, 20, 24* Young children have vague anxieties; they sense in their social surrounding that something is wrong *12, 14, 20, 24* Narrative restructuring of life and self-esteem *3*
Acquisited ESRF *14* →	#	#
Congenital ESRF *14* →	#	#

Information about ESRF and kidney-replacing therapies *3, 6, 20* →	May enlarge ability for self-care *6* Discontent about the information received (which is too difficult) brings about a search which makes less independent *3, 20*	<u>Positive:</u> - Reduction of uncertainty *3, 6, 20* - Leads to narrative reconstruction of the self-esteem *3* - Stimulates 'compliance' *3* - Leads to a developing of practical strategies *3* <u>Negative:</u> - Too positive ideas about the situation; disappointment *20* - Not necessarily better coping *6*
To 'choose' between different kinds of treatment *2, 20, 21, 22, 24* →	#	Making your own choices could cause stress *20, 21, 22* Being dependent on the choices of the medical staff *2, 22* (medical *20* , and psycho-social considerations *2, 20* financial capacity may be taken into account *2, 3, 5, 14*).) To cope with the refusal of the medical center for certain treatments. *24*

B: General medical experiences		
Factors as indicators of:		
A frequent recurring event as a consequence of ESRF	**Disruption of age related developmental tasks**	**Newly generated illness related developmental tasks**
Regular medical control or treatment; hospitalization *2, 6, 14, 20, 21, 24* →	It disturbs privacy *5, 14* Time-consuming, it demands rescheduling time *3* Double-life: clinic versus home; hospital school versus regular school *24*	(Routine) procedures leads to constant awareness of being ill: 'sickness-role-taking' *3, 9, 20, 21, 24* The amount of hospitalizations seems not to correspond with the amount of problems *6* Withdrawing from treatment due to fear *14, 20* Living as a boarder (This does not count for the situation in The Netherlands) *24*
Medical crises *3, 24* →	#	Dealing with medical crises *3* Confrontation with unexpected delay of transplantation or treatment *24* To worry about success of treatment *24* 'Theories' about influences on and cause of the illness *3, 13, 20* Aggression and frustration (as signal of the desire to get back one's health)*12, 24* The child experiences fear and guilt *7, 12, 14, 20, 24*
Progression of illness is vague; uncertain future *3, 5, 7, 12, 13, 14, 20* →	No planning for the future. *14* At an early age learning to cope with fear for death *3, 5, 12, 20*	Depressions *14* Denial *13* Nightmares *20* 'Short-life' syndrome *5*

Diet restrictions both food and fluid intake (from pre-dialysis to transplantation) *3, 5, 10, 12, 14, 19, 20, 24* →	Social problems during (dinner-)dates It is stigmatizing *3, 20* Minor daily stress influences the amount of compliance. *10*	The patient is considered to be responsible for 'compliance' *14* <u>Factors of influence on 'compliance':</u> - Social surrounding *3, 5* - Physician *3* , - Education *3* - Minor daily stress *10* - Becomes more difficult *19* - The accent is to much on obedience, to little on self-regulation *3* - Patient may have a different or wrong idea about the experienced effect of the diet: Feelings of hunger and thirst *3, 20*
Medication *3, 5, 14, 19, 20, 21, 24* →	Practical problems *3, 20* Is stigmatizing *3, 20*	Side-effects *12, 14, 20, 21* <u>Factors of influence on 'compliance':</u> - Fidelity to therapy is interpreted as caused by personality structure *3* - Patient may have a wrong idea about the experienced effect of the medication *3, 20* - Reason for incorrect using of drugs seen as caused by the physician-patient relationship. *5* - There is not always a direct relation between blood-counts and behavior, however the blood-counts are interpreted as indication of compliance. A consequence is false accusations and unjust compliments *20* - The accent is too much on obedience, too little on self-regulation *3*
Intense contact with medical staff *3, 12, 14, 20, 24* →	Overprotective medical staff (they have anxieties and habituation problems as well as the patients) *12*	Learning to cope with the uncertainties and interaction tensions in medical staff; This might result in problematic behavior *24* Being dependent on the medical staff *3, 5, 12, 14, 20*
Dealing with fellow-patients *3, 14, 22, 23* →	It makes social contacts possible *3, 14, 22, 23*	Mutual influencing: *24* <u>Stimulating:</u> - Self-help groups - Possibility to learn from each other's strategies *3, 14, 22, 23* <u>Negative:</u> - Hindering by depressive fellow-patients . *22, 23*

C: Dialyse problems		
Factors as indicators of:		
A frequent recurring event as a consequence of ESRF	**Disruption of age related developmental tasks**	**Newly generated illness related developmental tasks**
CAPD ('abdominal washing' at daytime) *20, 21, 22,* →	Tight daily schedule *3* Time-consuming: changing the fluid bag every four hours. *20, 21*	"A beast in my belly" *22* Complication: peritonitis *22*
CCPD (abdominal washing at night-time) *20* →	Committed to one's home at night *20*	#
Haemodialysis (machine) *5, 13, 14, 20, 21, 24* →	Time-consuming: = three times every week *3, 5, 21, 22* Demands rescheduling time *3* Travelling time: clinic<->home *24* Disturbing privacy *5, 14* Deprivation of social contacts *14* Family depends on dialysis team *24* Asking too much attention (as a way of coping) *14*	Getting used to the procedure *14, 22* Pain, nausea *14, 22* For young patients: first withdrawal and denial later on getting used to the situation *20, 24* Disturbed body image (for instance: too much attention to internal processes) *1, 6, 12, 13, 14, 20* Depending on a machine *5, 12, 13, 24*
Danger of Infection of the 'shunt' *14, 24* →	Not allowed to take a shower or to swim *14*	Often occurring medical problems *24*

D: Transplantation problems		
Factors as indicators of:		
A frequent recurring event as a consequence of ESRF	**Disruption of age related developmental tasks**	**Newly generated illness related developmental tasks**
Waiting for a donor-kidney *14, 20, 24* →	One has to be available constantly *20*	Looking forward to a transplantation, first: hope; enthusiasm lowered after information about pro's and con's *20, 24* Uncertainty about when the transplantation will occur *20*
Removal of the disfunctioning kidneys *14* →	#	#
(Sudden) availability of a donor-kidney; receiving a donor-kidney *5, 7, 12, 14, 20, 22, 24* →	New vitality (especially in children below ten years of age) *14, 20* Renewal of career perspective *12, 14, 20* Decrease of (diet) restrictions *20, 22*	Worrying about the success of the treatment *5* Getting used to decreasing of diet restrictions, first scared later on feeling relieved *20, 22* In case of successful treatment; first hope, then new anxieties *14* Fearing repel of the donor-kidney *5, 14, 20, 24* Getting used about the idea to have a donor-kidney; 'foreign body' *14, 20* Young children have no sense of guilt towards the donor, adolescents do have guilty feelings *7, 14* Feelings of guilt occur especially in case of living (family) donor *20, 24* (In The Netherlands hardly any living donors are used.) Unknown identity of the dead donor *14, 20, 24*
Repel of the donor-kidney *2, 14, 20, 24* →	#	Restarting haemodialysis may turn into a nightmare *2, 14, 20, 24*
Revision of transplantation *24* →	#	Even more fear for a second repel of the donor-kidney *24*

E: General physical problems		
Factors as indicators of:		
A frequent recurring event as a consequence of ESRF	**Disruption of age related developmental tasks**	**Newly generated illness related developmental tasks**
A poor general physical condition *2, 3, 12, 20* →	Fatigue, sleeping a lot, vomiting, irritation and depression *5, 20, 24* Delayed sexual maturation *20, 24*	Physical reactions are hold against the patient as psychosomatic *24*
Swelling up (in Pre-dialysis phase or after transplantation due to increase in appetite caused by steroid medicine) *14, 20* Or emaciation of the body (possible indication of 'malnutrition') *4, 14, 24* →	Eating disorders *24* Low self-esteem *6*	Disrupted body image *6, 12, 14, 20* Body source of grief, anger and uncertainty *20* In case of improvement of the figure: also improvement of the body image and improvement of the self-esteem *6*
Skeleton deformations a. In case of renal failure b. In case of transplantation as a consequence of medicine use *4, 7, 14, 20* →	Medicine against bone-weakening makes food tasting bad; 'compliance' difficult *14* Defective physical strength makes certain tasks difficult (for instance some IQ-test tasks) *4*	#
Anaemia *14, 20* →	Pale appearence and lustlesness *14, 20*	#
High blood pressure *14* →	#	#
Scars *20* →	#	#

F: General social problems		
Factors as indicators of:		
A frequent recurring event as a consequence of ESRF	**Disruption of age related developmental tasks**	**Newly generated illness related developmental tasks**
Stigma *3, 5, 6, 7, 22* →	Acting tough *22* 'How to tell the social environment?' *3, 6* Not daring to tell the employer about the illness *3*	'How to tell the social environment?' *3, 6* Low self-esteem as a reaction on the stigma *3, 5, 6, 7*
Changing family relations *3, 5, 6, 7, 12, 14, 20, 24* →	Overprotective parents *3, 6, 7, 14, 20* Strengthening family ties*3, 6, 7, 14, 20, 24* Disruption of family relations (marriage, siblings, social isolation) *3, 6, 7, 14, 20, 24*	Living with fear and feelings of guilt towards the parents *14, 20* Dependence on the family as a consequence of the illness *3, 5, 12, 14, 20, 24* Not everything can be discussed or shared with the family: sensing different problems and keeping the other person ignorant *7*
Intrusiveness: having to quit a job *3, 5* →	Deprivation social contact *3, 6, 7, 14, 20, 24* Lower subjective experienced competention *3* Financial problems *2, 3,5, 14*	#
Intrusiveness: disruption of the 'normal' school attendance *3, 4, 5, 14, 20, 24* →	Influences cognitive (in)competence as well objective *4, 14* as subjective *20* Limited imagination *14* Deprivation social contacts *3, 6, 7, 14, 20, 24* Limited social development *6, 7, 14, 20, 24*	#
Intrusiveness: disrupts 'normale' life on the whole *3, 5, 14, 20, 24* →	It disturbs privacy *5, 14* Deprivation social contact *3, 6, 7, 14, 20, 24* Limited social development *6, 7, 14, 20, 24* Becoming social independent is (especially for adolescents) difficult: lack of control over one's life*3, 5, 12, 14, 20*	Patients experience more intrusiveness than the medical staff notices *5* Loneliness and strong feelings of being an exception *3, 6, 7, 14, 20*