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95 – Parents of a Newborn Child With Severe Disabilities: Coping, Resources and Needs. A Qualitative Study.

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Parents normally expect their newborn child to be healthy but a few percent of newborn infants will turn out to have some kind of disability or inherited disease even in countries with neonatal screening. Parents, who realise that their newborn child is disabled, experience severe physical and emotional stress. They have to adjust their present life, dreams and goals to a different and unforeseen reality. Some parents adapt well to this situation whereas others report long term distress and difficulties (1). These outcomes do not always correspond with the severity of the condition. A former paper from this study reported that the diagnostic process had a significant impact on parental reactions and adjustment to the diagnosis, especially in cases where it was not possible to state a certain diagnosis (2). We have also reported about the severe daily strain from taking care of the child, very little sleep at night, fear of losing the child concurrent with very stressful interactions with the social service system in particular (3). In this third part we moved on to examine how parents deal with their on-going challenges and how to support them (4).

The aim of this study was to explore how parents coped with the birth of a severely disabled child, how they maintained their energy levels and personal resources to continue coping and areas where they struggled. The role and support of the social service system and the health care system were examined in detail.

We used a qualitative design to explore parents' experiences during a two year period following the diagnosis of a child's disability. Children with expected severe multi disability were included (see table 1).

Parents were identified at the paediatric ward at The Danish State Hospital in Copenhagen and interviews were conducted in the home of the family by the first author. Interviews were repeated two years after the first interview. Mothers and fathers were interviewed independently. Parents were allowed to tell their story and experiences freely and we specifically explored sources of daily stress, how the parents evaluated their situation, sources of resources and the interaction with the health care system and the social service system.

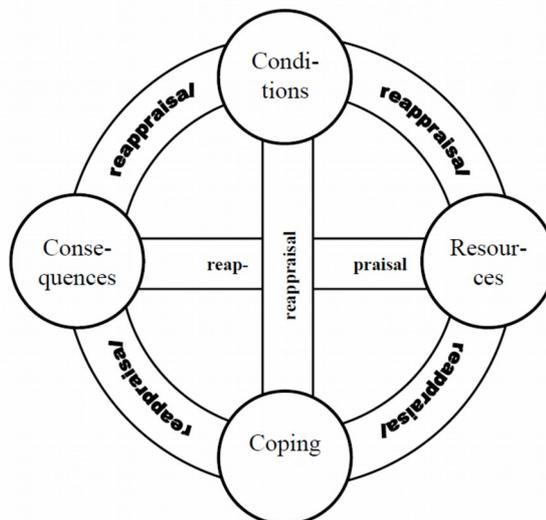
Findings were analysed with a Grounded Theory approach and interpreted in a theoretical framework of Lazarus and Folkman's theories on coping (5) and Fredrickson's Broaden-and-build theory of positive emotions (6), as well as theories of positive illusions and benefit finding during severe adversity.

We found that parents continually created and sustained their personal resources through positive cognitive reappraisals of their circumstances, the consequences of those circumstances and their coping possibilities. A model was developed in order to illustrate the intimate relationships between coping and resources (fig.1).

Table 1: Characteristics of the interview families

Sex of child	Age at interview	Siblings	Diagnosis
Male	2 months	First child	Unknown
Male	4 months	First child	Unknown
Male	8 months	First child	Infantile spasms
Male	10 months	First child	Unknown
Female	1 month	First child	Lissencephali
Male	4 months	First child	Unknown
Male	27 months	Sister 5 years old	Wolf-Hirschhorn syndrome, diagnosed 18 months old
Female	1 month	Sister 30 months old	Down's syndrome

Figure 1



Several coping strategies were identified that supported parents' maintenance of resources including; emotional bonding, identifying supportive social relations, creating mental respite, meaning-making, benefit finding, evaluating existential beliefs, taking action, normalization.

Parents were taking action in order to relieve the disabilities by, for example, joining elaborate exercise programmes other than those recommended by the paediatricians. By taking responsibility, parents were stimulating their own resources, as cited by this mother:

I feel, after joining the training programme, those families (in the programme), it's another ... it's a more optimistic view, that is easier for me to handle... because it is necessary, otherwise you don't survive this... and it's like we can do something, it is possible to make a difference.

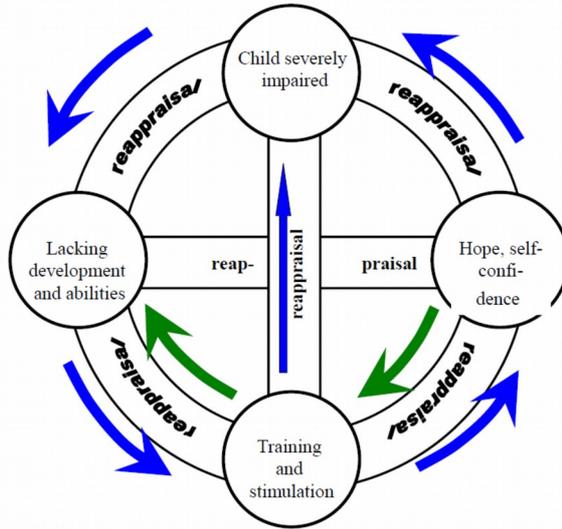
The resource-creating process from this activity is illustrated in figure 2 below. Blue arrows indicate expected effect of exercise on the child; the green arrows illustrated the resource-creating effect on the parents.

We also found both personal and circumstantial causes of resource deterioration, often caused by the parents' interaction with the health care system and social service system.

When parents had to apply, document, argue and participate in numerous meetings etc. in order to receive necessary help from the social service system this seriously deteriorated parental resources as stated by this mother:

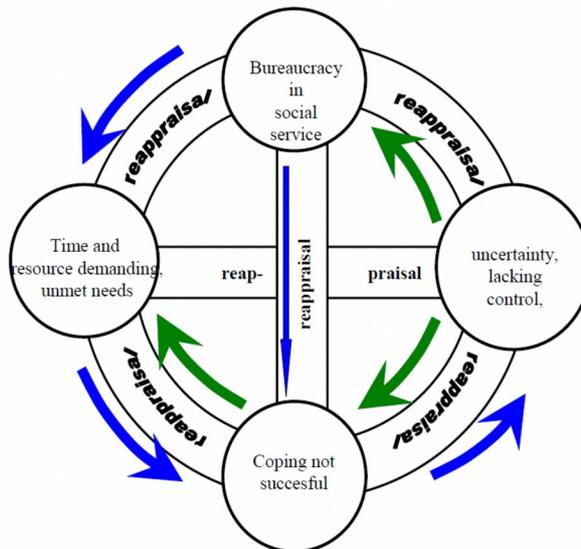
It feels like a fight. And it often feels demeaning. If I apply for something, I only do it if I really think it's something that I need. I would never apply for something that could be just nice to have; it would be nice to have a television for him, but such things I would never apply for... and you have to push for answers, and take care not to seem irritating, because they (the social workers) have so much power.

Figure 2



The effect on parental resources is again illustrated with green arrows, and the blue arrows illustrate the lacking effect regarding the strategy of obtaining help from the system. When experiencing bureaucracy, huge time expenses and uncertainty about their future due to the structure of the social service system, parents' resources deteriorated.

Figure 3



The strongest source for resource-creation was parents' appraisal of emotional bonds. Emotions for the child; love, responsibility and pride were essential. The communicative response from the child was vital in creating meaning,

bonding and hope. These positive emotions infused parents with energy and purpose in their continuing care-giving. Furthermore, a strengthened marital relationship and the experiences of family and friends contributed to forming a close family network.

Meanings and consequences of this study

The theory of resource-creation is proposed as an addition to the current understanding of coping and the role of positive emotions. Coping and resources were found to be closely interrelated thus parental coping can be strengthened by identifying and support the parents' resources.

Parents with a disabled child are at risk of chronic sorrow and depression, as found in recent studies (1;7), so intervention is clearly needed. Other studies of coping in this parent population have found poor parental coping was related to feelings of threat to the family, poor health in the family and lower family satisfaction (1).

As coping *can* be improved through intervention (8), it *is* possible for health professionals to support parents' resource-creation in a number of ways, even in very severe cases of disability as other factors in and around the child and the family often play a significant role in parental well-being.

Take home messages

- Parents of a disabled child experience severe stress in all domains of life.
- They may be at risk of developing their own mental and physical health problems, but many parents seem to cope quite well.
- Parental resources are closely connected with their ability to maintain caring for the child and cope with daily life.
- Coping and resources may be supported or counteracted by the health care and social service system.
- Emotional bonding to the disabled child is a main source of resource to parents.

Original abstract

<http://www.woncaeurope.org/content/bpop15-parents-newborn-child-severe-disabilities-coping-resources-and-needs-qualitative>

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