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## **Stabilising of Life: A substantive theory**

*Aino-Liisa Jussila, Ph.D.*

### **Abstract**

The purpose of this grounded theory study was to explore how families live after one parent has been diagnosed with cancer and to develop a substantive theory to explain how families solve the main concern in their lives. The study design was prospective using 32 joint couple conversations with parents of 13 families (N=26) during different stages of the cancer trajectory as well as 26 hours of observations of five families, including ten parents and nine children (N=19), collected during a boarding course on psychosocial rehabilitation. The data consisted of 2377 incidents and a memo fund of 97 pages. The main concern of families was how to respond to the shock of a parent falling ill with cancer. The core category was stabilising of life through facing of hardships and assuming an attitude towards the future which patterned out as detaching, fighting, adjusting and submitting.

### **Introduction**

Cancer as a disease influences not just one person in the family; instead, it can be perceived as a family disease since the falling ill of one family member affects the entire family and its well-being (Anderson and Tomlinson 1992, Åstedt-Kurki et al. 1999, Anderson 2000). Therefore, when one of the parents falls ill with cancer, it impacts the everyday life of the diagnosed person and their family members. In addition, the cancer patient's relatives or significant others find that the disease is a part of their lives (Eriksson 1996, Kuuppelomäki 2000, Eriksson and Lauri 2000a, 2000b, Eriksson 2001, Lindholm et al. 2002).

It is essential to include the family in caring for the patient and to treat the entire family as a patient, since the family has a great importance to the cancer patient. According to earlier research, however, the family may even be ignored and misunderstood by health care professionals, although the family with cancer has many issues to be addressed in order to be able to decrease anxiety and to be able to offer the emotional support that the patient requires. Thus, family life with cancer should be studied to improve health care of the cancer patients and their

families.

## **The Discovery Process**

The purpose of this grounded theory study was to explore how families live after one parent has been diagnosed with cancer and to develop a substantive theory to explain how families solve the main concern in their lives. The study design was prospective using 32 joint couple conversations with the parents of 13 families (N=26) at different stages of the cancer trajectory as well as 26 hours of observations with five families, including in total ten parents and nine children (N=19), collected during a boarding course on psychosocial rehabilitation. The data consisted of 2377 incidents and the memo fund of 97 pages. The data was collected and analysed according to the classic grounded theory methodology (Glaser, 1978, 1998, 2001).

## **A Grounded Theory of Family Survivorship through Stabilising of Life**

The substantive theory of family survivorship and its core category of stabilising of life provide a typology of strategies for families living with a parent diagnosed with cancer. According to this typology, families can remain in one type of behaviour or move from one to another. The properties of stabilising of life are *facing of hardships* and *assuming an attitude towards the future*. They are related to the feelings and actions prevailing in the family and, in turn, indicate that the family's stabilising of life, as regards facing of hardships and assuming an attitude towards the future, entails either detaching from the disease, fighting against the disease, adjusting to life with the disease or submitting to the disease.

Stabilising of life for a family with cancer either follows the sequence of behavior in accordance with the subcore categories or varies between the four behavioral patterns. The variation of stabilising of life depends on the situation-specific realisation of criteria representing the various feelings and actions involved in facing of hardships and assuming an attitude towards the future. Stabilising of life is manifested in the family based on different criteria depending on whether facing of hardships and the associated feelings and actions are life-embracing, persistent and active or powerless, dejected and passive, and whether assuming an attitude towards the future and the feelings and actions

## Pushing

The principal category and ultimately the title of the theory (*pushing*) developed from the words subjects used to describe the focus student's needs, the reasons they felt that the student should have access to advanced curriculum as well as descriptions of the actions taken by themselves (the pusher) to gain access to advanced curriculum. The group of words, seen repeatedly in interview notes were, 'push', 'pushing' and 'pushed'. Parents and educators viewed these students (perceived as having advanced abilities) as needing to be 'pushed'; as perhaps 'parent pushed'. Other parents and educators suggested that, while they not ones to 'push', they wanted students to progress. Time and again, the word push was used. As interview statements were coded and compared, more and more fit under the category of *pushing*. At times, words were used that were synonyms of pushing such as advocated, look out for, supervise, etc. These were sorted into the *pushing* categories where they fit best. Once the main *pushing* category was found, the coded data and memos were compared and sorted, seeking the stages of *pushing*. These stages became *investing*, *pressuring*, and *lobbying*.

*Pushing* can be defined as exerting oneself continuously, vigorously, or obtrusively to gain an end or engage in a crusade for a certain cause or person; in essence, becoming an advocate for a particular cause or person (Wordnet, 2006). This definition presents *pushing* as a positive action. In theory, educators are the pushers or advocates for all students (Mann, 1848). Parents are the pushers or advocates for their children (Crozier, 1997). So how do seemingly positive notions create conflict? The problem lies in who is deemed deserving of challenging material, all children or specific children? If all children do not receive access to advanced mathematics content, how are those children who should receive the attention and material selected? Although neither a plot nor scheme, pushers are fighting to garner access into classes with an elite group of students receiving advantaged instruction (Kohn, 1998; Oakes & Wells, 1998; Spear, 1994). The pushers do not want their focus students to learn with the remaining average or below-average majority.

There are three levels of *pushing*. Some pushers may work at all of these levels over a period of time while others may

related to it are positive, hopeful, meaningful, balanced and trusting or negative, hopeless, anxious, fearful and doubtful. The variation in stabilising of life is manifested as variation in the different stages included in its four different behavior patterns.

### **Detaching from the Disease**

The life of a family detaching from cancer is marked by *maintaining of hope*, which is characteristic of the atmosphere in the family throughout the process of detaching from the disease. As hopes of recovery awaken, the family maintains hope supported by the recognition of dispelling concerns and optimistic thinking. This is manifested in the family's positive attitude towards life and their active role in detaching from the disease. In the family's process of detaching from the disease, maintaining hope is followed by *living trustingly*. In this phase, family members live in the present as fully as possible trying to avoid the effects of being ill. When the family is balanced and shares an atmosphere that evicts concerns, family members live trusting in the future. There is trust among family members in detaching from the disease and dispelling concerns, and they strive actively and trustingly for the future.

Despite detaching from the disease, suffering from cancer does not pass without effects in the family. When the family members' life values change while living with the disease, and spiritual growth and reinforcing of self-esteem take place, the family's *self concept changes*. In this stage, the active pursuit of meaningfulness in life, which is built on a new set of values, is now more pointedly evident in the family members' lives as they strive for detaching from the disease.

*Progressing of recovery* is, in a way, a turning point towards better, as it consists of feelings and actions associated with becoming motivated in self care, increasing of treatment satisfaction, restoring the zest of life and facilitating of life in the family. When family members take care of the parent and promote his/her recovery, treatment satisfaction increases. This, in turn contributes to restoring the zest of life thereby facilitating the life of the family. The active nature of the family, a positive attitude in treating the ill family member, and a feeling of meaningful life promote the patient's feeling of recovery and detaching from the disease. At the same time, facilitating of life amidst the disease appears more and more real.

*Continuing the habituated life* releases the family from the circumstances of the disease and enables the detaching from the disease and the continuing of normal life. When the family's life returns to normal and when the relationships have remained the same despite the disease, the family can resume normal, everyday routines. Resuming the former life is also manifested in a positive attitude towards life, a balanced atmosphere in the family, and the feeling of meaningful life as the family detaches itself from the disease.

### **Fighting against the Disease**

In the atmosphere of a family fighting against the disease, becoming surprised by the disease and grieving over falling ill enter into the first stage of the process of fighting against the disease. *Deliberating about falling ill*, which starts the process of fighting against the disease, comprises the emotions and actions linked to becoming confused by the disease and seeking reasons for falling ill. After the family hears about the disease, they are perplexed and start to deliberate about the disease. Then, the fearful and anxious atmosphere prevailing in the family is strengthened by the active seeking for reasons for falling ill.

In the family's process of fighting against the disease, deliberating about falling ill is followed by *rebellious against the change in life*. In this phase, family members gather up all their resources in order to resist the disease and to prevent it from taking the upper hand. When deliberating about life becoming more difficult, the family rebels against the change in life brought about by the disease and criticises the patient's treatment in order to bring about changes. Prevalent is a critical and rebellious but also guilty atmosphere on the one hand, and on the other hand, unyielding and life-embracing behaviour aimed at evicting troubles within the family. These intertwine with a feeling of hopelessness towards the future as the family fights against the disease.

*Overcoming adversities* is an expression of the family's strength in the process of fighting against the disease. When the family takes responsibility for the patient's treatment and creates fighting morale, they keep up the overcoming of adversities by processing their worries and by dispelling the feeling of disease among them. In this stage, the family overcomes the feelings of hopelessness with their own activity as

they fight the disease.

In the process of fighting against the disease and overcoming many adversities, people prepare themselves for the after-effects of treatments and for the deterioration of the patient's present condition. *Preparing for worse* involves feelings and actions related to getting accustomed to the after-effects of the treatments and to preparing for a decline in the patient's condition. When the family is preparing itself for the after-effects of treatments, it is simultaneously preparing for worse by anticipating a decline in the patient's condition. In the fight against the disease, this is manifested in a feeling of anxiety in spite of active and life-embracing actions.

*Ensuring functionality* enables the fight against the disease. It involves feelings and actions in the family relating to securing the future, bearing responsibility for the family, protecting close ones, rationalising the facing of disease and adopting a new way of spending time. Family members are ensuring the functionality during the parent's disease by aiming in different ways to secure the future. Moreover, they aim to bear the responsibility for each other, protect each other from the negative effects of the disease, rationalise their attitude towards the disease as well as adopt a new way of spending time.

### **Adjusting to Life with the Disease**

*Clarifying of facts* begins the process of adjusting to life with the disease. In this phase, assuming a serious attitude towards treatment and realising the limited scope of the future are central features of the family's atmosphere. When the nature of the cancer becomes clear, the facts relating to the disease are clarified and the family starts to live according to the realities brought about by the disease. At first, the atmosphere in the family is dejected, but little by little, the family members begin to act according to the situation as they adjust to life with the disease.

In the family's process of adjusting to life with the disease, clarifying of facts is followed by *resorting to help*, during which the family members seek to find relief from their difficult situation. Family members experience finding relief not only in contacts to others close to them or in their philosophy of life, but also in resorting to the individual resources and relying on the expertise of various professionals. In this phase, despite the

prevalent anxious atmosphere, family members aim to overcome the feeling of powerlessness prevailing among them as they are adjusting to life with the disease.

*Returning to life* is an essential phase in the parent's and his/her family's process of adjusting to life with the disease, whereby the family members feel concretely that living with the disease is possible. As the family becomes accustomed to changes in life, family members begin returning to life by means of being perplexed by the ending of treatment, attaching to the present and processing being ill. The atmosphere in the family is hopeful and the feelings towards the future are trusting as the family adjusts to life with the disease.

As life is stabilising, the feeling of togetherness among the family is deepening with the process of adjusting to life with the disease. Suffering from a disease results in an *intensifying of togetherness*, both by strengthening the intimate relationship and unifying the family, as well as by bringing their immediate circle closer together. Thereby, in the family's atmosphere, signs of hopefulness, but also helplessness may be detected as the family members are adjusting to life with the disease.

*Maturing through hardships* enables the family's adjusting to life with the disease by maintaining equilibrium and realising the importance of looking after oneself. In so doing, the family notices a higher level of acceptance of circumstances in comparison with the early days of suffering from the disease. Maturing through hardships is manifested within the family both as noticing the hardships caused by being ill and as realising the solution to them as the family is adjusting to life with the disease.

### **Submitting to the Disease**

*Life coming to a standstill* begins the process of submitting to the disease, wherein family members are shocked to hear about a parent falling ill and may even experience feelings of panic and fear of death. They feel as if their entire life is coming to a standstill due to feelings of shock caused by the grave nature of the disease. Then, an atmosphere of giving up and surrendering prevails as they submit to the disease. This sense of surrender is especially enhanced by uncertainty about the nature of the disease and fearfulness towards it.

In the family's process of submitting to the disease, life coming to a standstill is followed by *succumbing to fear*, when different kinds of feelings of anxiety spread from one family member to another. As dreading the different treatments spreads in the family and being ill as such is felt as a source of concerns, family members are comprehensively overcome by fear. Then, the atmosphere in the family is dominated by a dread directed towards the disease itself, receiving treatments for it and living with it, all of which contribute to succumbing to fear.

Succumbing to fear is followed by *being burdened by concerns*, whereby the disease has become a permanent burden in the life of the family. Along with being burdened by concerns, life for the family becomes more difficult and stabilises by submitting to the disease. When the family becomes aware of the parent's deteriorating condition, they feel that concerns and hardships are nearly overwhelming. A powerlessness and passivity in evicting troubles and an uncertainty towards the future emerge among the family.

*Life turning more difficult* complicates the everyday life of the family and attaches the life of the family to submitting to the disease. When the everyday life of the family becomes burdensome and the relationship between the parents faces the crisis caused by the disease, the life of the family becomes more difficult and family members become depressed. The entire immediate circle experiences feelings of dejection. This is manifested in the family as passivity and hopelessness as well as submitting to the disease.

*Getting caught in being ill* attaches the family to the circumstances of being ill and ties them to submitting to the disease. When the family, in a way, clings to being ill and family members grow tired, the family undergoes getting caught in being ill. The disease takes control over the everyday life of family members and submitting to the disease deepens. Among the family, this is manifested in life's filling with the disease.

## **Discussion**

Many deductive studies have identified the impact of an adult's cancer diagnosis and treatment on the functioning of the family and their importance in relation to the patient's and the family's adjustment to cancer (Cooley & Moriarty, 1997). In addition, many researchers have found that a family member's

cancer diagnosis is the family's concern and affects the entire family (Cooley & Moriarty, 1997, Shepard et al., 1999). There is a link between a patient's feelings of helplessness or hopelessness in the face of cancer and inappropriate communication among the family members (Inoue et al., 2003). There is also evidence that the cancer diagnosis of an adult family member is a shock to the entire family (cf. Mellon 2002).

This inductive substantive theory of family survivorship (Jussila 2004) has the core category of stabilising of life as a response to the shock with two properties: facing of hardships in the family and assuming an attitude towards the future in a family. The emergent theory and its typology of stabilising of life include some similar characters to the family survivorship model (Mellon & Northouse, 2001, Mellon, 2002), derived from the resilience model of family stress, adjustment and adaptation according to McCubbin and McCubbin (1996). According to the family survivorship model (Mellon & Northouse, 2001, Mellon, 2002), the illness survival stressors relate negatively to the family's understanding of cancer. These stressors include concurrent family stressors, fear of recurrence, and somatic concerns. Furthermore, family resources, such as the resoluteness of the family and social support for the family, relate positively to the family's understanding of cancer. Moreover, the family's understanding of cancer relates positively to quality of life and mediates the effect of the illness survival stressors and the family resources. (Mellon & Northouse, 2001, Mellon, 2002.) Therefore, the family's quality of life is strongly related to facing of hardships and assuming an attitude towards the future in the family, which are the two properties of stabilising of life. Thus, the outcome variable of the family's quality of life in the family survivorship model by Mellon and Northouse (2001) has some similarities with this substantive theory of family survivorship and its typology of stabilising of life, although this inductive theory has its own unique and powerful character.

Families perceive stabilising of life as essential in their survivorship. Stabilising of life in a family of a parent suffering from cancer has similarities with the theory of reconstructing reality in a family of a child with recently diagnosed cancer (Clarke-Steffen, 1997). The families view reconstructing reality as creating a new normalcy. During the transition of living with

childhood cancer, families are using strategies of managing the flow of information, reorganising roles, evaluating and shifting priorities, changing the future orientation, assigning meaning to the disease and managing the therapeutic regimen. (Clarke-Steffen, 1997). Hence, the character of the process is involved in reconstructing reality as well as in stabilising of life in order to continue living in the family with cancer.

Stabilising of life in a family is closely connected to normalizing of life on an individual basis, as stated by Killoran et al. (2002), when long-term survivors of metastatic cancer attempt to normalize their lives through the process of self-transformation. It is characterised by viewing the diagnosis as insignificant; questioning the diagnosis or disbelieving the severity of disease; not worrying; not questioning the cause for the disease; and explaining the recovery in terms of faith in medicine, spirituality and personal volition (Killoran et al., 2002). Stabilising of life is also closely related to the process of transforming personal tragedy on an individual basis through different phases identified as encountering darkness, converting darkness, encountering light, and reflecting light among breast cancer patients (Taylor, 2000). The similarity between a family's stabilising of life and an individual's normalizing of life through transformation is found in the character of the process, although stabilising of life has its own character in the typology as well.

In this research, the typology of stabilising of life consists of detaching, fighting, adjusting and submitting. The typology of stabilising of life in a family with cancer is now compared to the typology of functioning of the family during the palliative phase of cancer according to Kissane et al. (1994). Cohesiveness, expressiveness and conflict are the parameters in differentiating adaptive families from those coping poorly and those whose members develop psychological morbidity. The members of supportive families with high cohesiveness have a low level of psychological morbidity and function competently in the social world. Accordingly, supportive families have similarities with families behaving in a detaching manner during stabilising of life. Supportive families as well as conflict-resolving families have low psychosocial morbidity, while ordinary families with intermediate levels of cohesion, expressiveness and conflict experience somewhat higher psychosocial morbidity. Therefore, the character of conflict-resolving and ordinary families

resembles the character of families behaving in an adjusting manner during stabilising of life because the number of conflicts, differences of opinion and negative feelings is tolerable. Furthermore, hostile families with a great number of conflicts have the highest levels of psychological morbidity and poorest levels of social adjustment and have some similarities with the families behaving in a fighting manner during stabilising of life. On the other hand, sullen families having some conflicts, poor cohesion and limited expressiveness resemble the families behaving in a submitting manner during stabilising of life. (Kissane et al., 1994.)

This substantive theory of family survivorship (Jussila 2004) provides researchers, health care professionals and educators with a greater understanding of the perspectives of caring families with cancer in health care. It may also be used in developing the health care of families and in developing the education of health care professionals.

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