

Uncertainty as organizing principle of action – teenagers living with parental somatic illness

Abstract

Uncertainty as condition for teenage life when confronted with parental serious illness is presented as the main challenge characterizing this situation. Based on the teenagers own accounts narrated in 26 semi-structured interviews we are able to provide an analytical description of important ways in which parental illness affects every-day life of the teenager. Findings suggest various changes and challenges in family roles and caring patterns, emotional oscillation, changes in relation to peers and conflicting motives and tasks. These changes are linked to the impact of the uncertainties of the illness situation. A model of uncertainty is proposed which illustrates how various events feed into the underlying uncertainty and fear of losing the parent. The model thus addresses the situation, where the teenagers are compelled to making firm divisions between a private-life world and a social life-world as well as between a family life-zone and a youth life-zone.

Key-words: parental illness, illness phases, uncertainty, emotional oscillation, teenagers

Introduction

Serious parental illness and potential parental loss for children and teenagers is premature, untimely and culturally as well as existentially unexpected. Pattison already in the late 1970'es remarked that advances in the medical technology had prolonged the living-dying interval; that is the time between diagnosis of a fatal disease and death (Pattison 1978). Since then this tendency has only increased, which means that more and more children and adolescents are living in families which have to cope with the severe challenges of critical somatic illness for many years. There has been a growing research interest in those children who are living with a seriously ill parent and this period is recognized as developmentally significant (Christ et al. 2002). Serious somatic illness in the family affects and changes the family system in its totality; but also each member is affected individually, albeit differently from others in the family (Rolland 1999). There are distinct perspectives, needs, responsibilities, roles and developmental tasks that differ between family members. Reactions of parents and children to the illness are not necessarily aligned, and parents tend to consider their children to be less distressed than what the children themselves report (Gabiak et al. 2007). Despite more openness in the communication and involvement of children in relation to prognosis, treatment procedures etc. compared to former practice, this may not necessarily imply openness about emotional reactions among family members related to the illness (Thastum et al. 2008). Adolescents are found to experience more adjustment problems, as compared to younger children, when faced with serious parental illness (Bierenbaum et al. 1999, Grant 1995). Christ et al. 1994 argue that teenagers are capable of

understanding the impact of the illness and therefore also suffer through more intensive worrying: *“Compared to younger children, the adolescents greater cognitive and empathic capacities allowed them to be more aware of losses and of the parent’s physical and emotional pain”* (ibid: 604). Teenagers are more likely to substitute their parents in relation to obligations in the household, and thus find themselves in conflicting “pulls” between tasks related to their home and tasks related to their own teen-age life with peers, school and leisure time activities (Christ et al. 2002). Also distinct for the age-group of teens is experiencing more conflicting dilemmas between autonomy versus attachments to the ill parent (Bugge et al. 2008). With this in mind it is important to supplement a systemic family-approach on the impact of illness, with an investigation, which privileges distinct teen-agers perspectives on their own experiences of what they are going through and how they perceive matters.

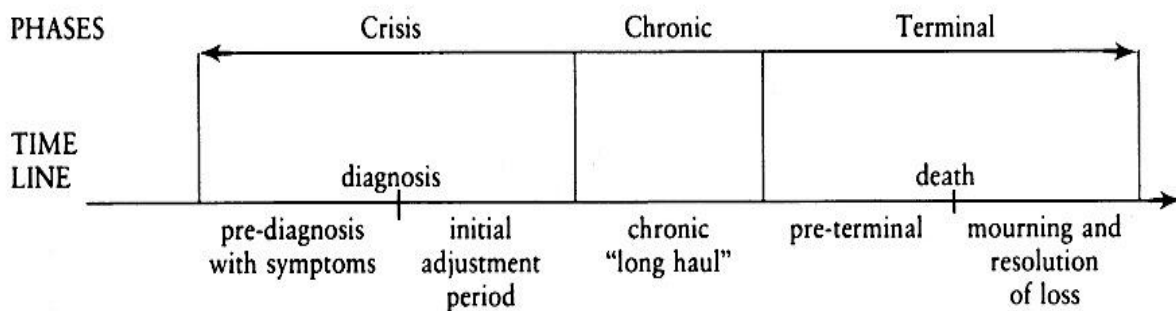
Research findings on children’s typical reactions to illness in the family

Gabiak et al. 2007 found in their comprehensive literature review (including 45 international empirical studies) that adolescents with parents suffering from cancer shows higher levels of anxiety, externalization and behavioral problems than their age-mates controls and that these symptoms increased when both parents showed depressed moods. Visser et al. (2004) concluded, in their review, that communication patterns and openness about the illness proved to help the teenagers cope with the situation. Within the adolescent age group, early adolescents (12-14) tend to show more avoiding behaviors and social withdrawing in the family, than their older counterparts who tend to confront the dread of the situation more directly and also participate more willingly in care and housekeeping activities (Christ et al. 2002). Feelings of guilt, fear, sadness, anger, loneliness, somatic complaints, and decline in academic performance, are prominent reactions, and these troubles are more enduring in those teenagers living in families where the parents are severely distressed (Dyregrov 2012). Also these reactions are more intense when there is a limited social network, and when the quality of that network is poor, i.e. when friends and peers avoid talking about the loss/situation (Engelbrekt 2005). Equally noteworthy is the finding that social isolation/loneliness seems to cut across life-worlds, so that those respondents who are not sharing emotions at home, are also likely *not* to share emotions with peers/friends (Ibid). This may suggest that an open atmosphere in the home environment help the teenager to establish openness in their relationships with friends/peers. Girls report more troubles than boys, generally, and boys tend to be more occupied with the developmental task of separation from parents than girls, who are more likely to become involved in the practical sustainment of the household and caring for their parent during illness - especially in families where the mother is ill, and in single parent families (Grant & Compas 1995, Christ et al. 2002, Dyregrov 2012). In short, we learn from this field of study that parental somatic illness is not only

representing a severe problem in the here-and-now daily well-being of the adolescent, but also potentially complicates developmental tasks of separation-individuation, i.e. the formation of an autonomous identity, and investments in own formative activities, which are characteristic for adolescence (Diareme et al. 2007: 102).

Systemic theoretical approaches to serious illness in the family

Theoretical models describing illness processes and reactions towards somatic illness are sparse in the literature, but a few important sources from a systemic family approach are mentioned here. Rolland’s family systems framework, serves as a descriptive framework for understanding the impact of the illness on the family by regarding the illness as an ongoing dynamical process imposing changing demands and challenges upon the family. Rolland suggests that the process includes transitions and landmarks, which are demanding constant adjustments to new changes, but overall three phases can be identified:



The first phase is marked by crisis and involves the initial adjustment around the onset of the illness (identifying symptoms, receiving a diagnosis and adjusting to prognosis and changes in expectations to the future). This phase and its challenges to a large part relies on the nature of the onset of the illness (acute or gradual) and its prognosis (likelihood of its curability). Rolland’s research suggests that communication patterns and openness within the family in this initial phase in order for the family to remain a unity and accomplish a “we-ness” around the handling of challenges together is of vital importance. Gradually, everyday life is re-established (but on new terms) and this period is described as the chronic phase, in which the family members - together and separately - get used to some of the implications of the illness and its bearings on everyday life and conditions, while at the same time they are also constantly re-adjusting to new progressions in the illness (practically, emotionally, economically). Rolland describes the two first phases as principally open in relation to prospected outcomes, which is the major difference to the third and final terminal phase – a pre-terminal period, where the family struggles to come to terms with

death. Rando's work on anticipatory grief, is relevant to this pre-terminal phase, as she explores reactions and grief connected to the anticipation of the permanent loss. *"Anticipatory grief mandates a delicate balance among the mutually conflicting demands of simultaneously holding onto, letting go of, and drawing closer to the dying person. A critical task is to balance these demands of conflicting pulls and cope with the stress that this incongruence generates"* (Rando 1986:24). The time with illness, in many cases come to constitute a pre-loss period as that time represent not only the first steps in a natural history of post-death grief reactions (Siegel et al 1992), but also the illness in itself represents what P. Boss (1999) has termed an ambiguous loss. Characteristic of ambiguous loss is ambivalence and unresolvedness in the role and membership-status of a person in the family system, and is often described in connection with a family member falling seriously ill (Ibid). These scholars all underline that illness cause ambivalent losses and conflicts in close relation to the level and presence of uncertainty and unpredictability in the individual case. Rolland's phase model illustrates a canonical process of a "typical" duration of a fatal progressive illness, and is useful to identify challenges related to these phases however capturing first person perspectives from family members are not included in the phase-model. The present study captures teenage children's first person perspectives and thus aims to supplement Rando's approach in this respect. The co-constitutional dialogical unity between person and environment is taken as ontological point of departure when investigating the open dynamical system within which development takes place (Valsiner 1997). Translated into the study of teenagers living with seriously ill parents this implies a radical openness towards those tasks and problems, challenges and meaning construction, which the teenagers themselves present in personal narratives about their life and situation, and voice in the interviews, possibly as fragments of the wholeness that constitute a personal life-world in movement, from the point of view of the subject. In the remains of this article, aspects of the inherent uncertainty characterizing the illness process are explored from the teenagers' first person perspectives. This implies an ambition to connecting the existential position of living in the turbulence of the illness, in fear of losing a loved parent as a teenager with how this situation inflicts on participation in relevant life-worlds at home and in youth-life.

Presentation of the empirical material

The present study is based on a research project, which is funded, designed and carried out by the NGO, *Grieving Children, Teens & Young Adults - Danish Counselling and Research Centre*. The centre provides free professional counselling in groups or individually to children, teens and young adults (->28 years) who have lost a parent/sibling or who are next of kin to a seriously ill parent or sibling (in separate groups). Informants for the study were recruited through newspaper adds, radio-programs, facebook adds, and the homepage of the organization. Ten informants were recruited from the counseling center, the rest of the

informants were recruited through those other channels. All 26 informants volunteered and handed in written informed consent, and were thereupon briefed in relation to anonymity as well as to their rights to withdraw their participation and consent at any time. For those participants under age 18 consent forms from a parent was also obtained. The interviews took place in the counseling centers in the three big cities in Denmark: Copenhagen, Aarhus and Odense and in two instances the interview was obtained at the home of informants. All interviews were conducted by a trained clinical psychologist or a researcher, and transcribed in full by the psychologist and two research assistants. Six informants were aged 13-15 and twenty informants were aged 16-19, only three were boys in the original material of Interviews conducted in years 2008-2010, transcribed in 2011 and analyzed by the author in 2012. Three more interviews with boys, all conducted in 2012, by the author, supplement the material in order to achieve a more valid gender balance.

Interview-guide and themes

All interviews lasted between 90 – 120 min. and informants were interviewed according to a semi-structured guide (Kvale & Brinkmann 2009) with the overall aim of understanding more fully the implications for teenager's involvement in their parent's illness. The semi-structured guide consist of questions related to background information (incl. diagnosis, parents job situation, age etc.) relations within the family (between parents/children/siblings, between parents) the process and duration of the illness (onset of the illness, the recalled reactions, changes in the process, perceived severity, social network and support) the teenagers involvement in the illness (practically and in relation to various forms of care, and changes in involvement during the illness), changes in self (feelings of being different from peers, self-worth, and a checklist of typical ways of coping). Finally all informants were shown an old-fashioned weighting scale, illustrating the tipping balance between their lives as young persons and their lives in the family with a sick parent, the were then asked to reflect upon their way of balancing these issues. All interviews were concluded with a debriefing (was it alright to talk about these issues? Do you feel alright now?). All participants were offered the opportunity to talk more with a counselor and they were informed that they were welcome to call the open line and ask for a counselor if they ever felt like it.

Analytical strategies

The empirical material consists of more than 600 pages single spaced and it was read through twice in its entirety in order to get a general feel of the material. All case-stories were then systematically coded in relation to research questions and emerging themes. These were then categorized according to the process of the illness, levels and kinds of uncertainties across time, hope/anxiety and meaning-making,

relations/role and conflicts in the home and in school with peers, perceived coping strategies and resources. Often in qualitative studies the analysis involves deep and comprehensive presentation of a few cases from which more general themes and coherence are identified (Kvale & Brinkmann 2009). This procedure is less appealing in regards to the present study involving 26 individual case-stories. In order to make the most of this comprehensive material it makes more sense to group the interviews into particular kinds of illness experiences at particular times during the illness. "The general picture" of everyday life with a seriously ill parent, is thus based on readings of each case-story categorized as corresponding to one in four different psycho-social illness phases, at the time of the interview. In this way we can substantiate Rolland's model with first person perspectives on particularities regarding the experience of dynamical changes of the illness over time - and from there identify general findings. The aim of this article is to present characteristics of uncertainty in each phase of illness, in order to validate and substantiate the general model of uncertainty as organizing principle of action. More in-depth qualitative "thick descriptions" of particular themes and dynamics within these, will be explored and presented elsewhere, in future publications.

Presentation of the informants in relation to psycho-social illness groups

Six informants had parents with a *Progressive illness of an episodic kind*. These illnesses are life-threatening (both objectively and experienced as such by the children) and often acute. As an example one girl's mother suffered from returning blot-clots, another girl's mother was awaiting a new kidney; then nearly died during the transplantation, and fell ill with infections several times after the transplantation. Common to stories of this category was a fairly long period of time with illness in the family (averagely the parent had been ill for 6 years) and in a dramatic and turbulent episodic way. In this group we found some of the most troubled and traumatized teenagers in the material (suffering from intrusive images of panic situations, high anxiety levels etc.). The combination of the acute-life threatening stressors (jumping whenever the telephone rings) and their occurrence over a long time-span probably explains this finding.

Seven informants had parents with progressive illnesses with a yet open-ended out-come. Mostly these parents suffer from various forms of cancer, (breast cancer, cancer in the uterus/large intestine). Average time since diagnosis was 3 years at the time of the interview. Common to these stories is a prominent oscillation between hope for a cure and fear of the worst – as well as reflections regarding potential relapses even - if the parent is to respond well to treatments. Also in this category we find teenagers who are relatively well-functioning, and also pre-occupied with other issues in their lives than their parent's illness. In this group most ill parents are not too incapacitated, and often the ill parent is also him/herself optimistic about his/her future cure and return to health.

Seven informants had parents with a Chronic/Constant condition – which means illnesses that you die with rather than from. In this group the time with severe illness in the family is averagely 5 years. Four of these seven are in a situation where both their parents are ill (either one or both chronically and/or one progressively). One girl's mother has been chronically ill with rheumatoid arthritis all her life, and her father was diagnosed with ALS three years ago, another girl has had a mother with MS since the girl was 12 and a father now ill with a brain tumor. Common to these four girls is that they are 17-19 at the time of the interview and in this group we find teenagers with the most comprehensive caring obligations and those most intensely emotionally involved in their parent and the illness.

Six informants (average age 16) had parents with a *Progressive illness in the pre-terminal phase*. In these stories a process with a clear and fast progression in the illness, with no positive reactions to treatments is presented. One parent suffers from ALS (but keeps impressing the doctors by living on), one has a mother who is sick with cancer in the lymphs, one has a father with brain-cancer). The average time with illness in the family has been 3 years, and in this group we found the most immediately distressed teenagers (all six informants were in some sort of psychological treatment and some with clinical depression). Three of the six informants have a parent in the acute pre-terminal phase - one teenager even knows when her father is going to dye, because a respirator is going to be switched off three months ahead of time at the interview.

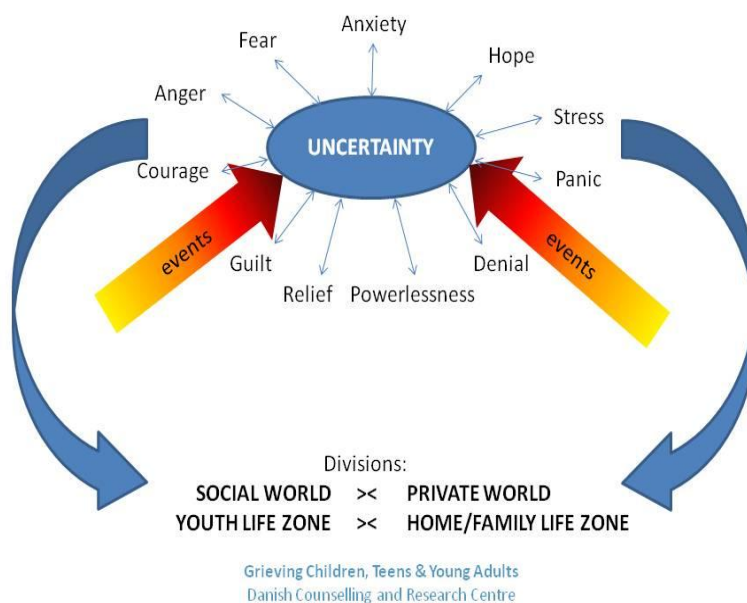
Problematizing categorizations, inclusive categories and co-morbidity

It has proven difficult, in many cases, to categorize the psycho-social type of illness– and there are several cases where the illness has returned, so that the present story, is actually the second time round that the teenager is confronted with the fear of losing their parent. Further, there are several cases of co-morbidity, in which the parent without apparent illness also suffers from depression (eight cases) and/or abuse of alcohol (in three cases). All categorizations are based on the teenagers own stories and the researchers interpretation of them in relation to the present situation. Those categorized in progressive pre-terminal phase are thus those who report that doctors have predicted a few months left to live – in some of these cases that situation has been predicted many times, and the parent keeps “cheating death”, so the pre-terminal phase has its own “long haul”. When placing stories in the Chronic/Constant category, these should only include cases where the illness is severe and serious, but not life-threatening. However, experiential truth may not, and are often not aligned with “Medical truth” and three teenagers, have for long actually feared and strongly believed that their parent should die from the illness – this fear significantly colors their stories, and over-all well-being.

Findings

By suggesting the model of “uncertainty as organizing principle of action”, we enter into an ongoing debate with important clinical implications – we argue that painful uncertainty of loss is at the heart of the situation when living with a seriously somatically ill parent, and that this situation is radically different from bereavement; i.e. a situation where the painful certainty (of the permanent loss) is at the heart of matters, although the impact of the permanent loss is not realized immediately (Christ et al. 2002).

Uncertainty as organizing principle of action



The most striking similarity across cases in the material is that all teenagers describe an everyday life where uncertainty is ever present like a shadow to all objects held against light, more or less pervasively in all relevant experiential timeframes and across the phases. This is so, both in regards to what will happen now and how things will be in the next few days and weeks, or even over longer periods of time i.e. the next months and even years. In those families where the illness is of an episodic character the drama and intensity of sudden changes is most prominent, and acutely stressful, but also in more chronic conditions where the pace of developments is slower and more constant – uncertainty still prevails just within a longer time-horizon. Not knowing when and what is really going to happen – and if the situation is lethal at all (e.g. in those cases where there is a positive prognosis- or in cases where the parent despite predictions keeps living) is a tiresome and stressful situation to be in. The uncertainty becomes the situational imperative which is constraining their live-world and setting of priorities, not only in relation to the home and the illness, but also in relation to other spheres of their lives. Events of various kinds feed into the uncertainty

situation and works as signs translated into the meaning making process related to the uncertainty - often pointing in different directions and with ambiguous implications oscillation between hope and fear: does this mean that she gets well? What if this means she is worsening? The events are internalized and thus enter the personal life-world and cause immense emotional oscillations. In the following a presentation is described of how uncertainty informs subjective experiences in different phases of the illness, and the mechanisms of dividing life-worlds is identified as a way of handling the unpredictability and uncertainty overlying all dimensions of the process.

Uncertainty in the phase of crisis

Not all informants have any recollections of the illness onset; especially those with parents with a chronic condition, there are few recollections of a time before the illness. Those who do remember the onset produce vivid and comprehensive accounts: They recall their where-abouts, who told them about the situation and how, and immediate reactions around the time of the first symptoms, the diagnosis etc. all in great detail. Some immediately reacted with horror and fear of losing their parent as a result of the disease: *“just the word cancer – you know – the word itself you just think - death!”* Others remained calm and relied on their optimism and good faith: *“In the beginning we were alright, actually...also because my mother was doing alright, and we continued what we were doing, but then it sneaked in on me. What if this means....you know”*. Often these more moderate reactions were aligned with actual positive prognostics (i.e. breast cancer) – and their parents own optimism. But this connection to actual prognosis and perceived fear is far from straightforward. One boy strongly believed that the doctor and his parents were hiding the truth from him (and that his mother’s condition was lethal progressive rather than chronic, this conviction was stronger than what he was told, and could read for himself about his mother’s illness). Also, in those cases with a positive prognosis the fear of a potential (and statistically heightened risk) of a relapse become prominent at times *“what if it spreads? or what if they just have not found it all yet?”* A final third group found it very difficult to relate to the message, take it in, and understand the potential implications. *“it was just unbelievable – that my strong father, should be seriously ill – I could not understand it. It was like I could not hear what they were saying”*. Then follows a time of foggy, confused and unstructured stories – Just as vivid the reconstructed memories are of the very first experiences with parental illness, just as strikingly is the lack of structure and organization surrounding the narratives of the first period of some months after the diagnosis. Typically they have vague ideas about several hospitalizations, or the first medical treatments (but not when this treatment started), or they describe this time as simply a time of dark. *“I just remember that my mum cried a lot, and that everything went dark in that time. It is like a fog, really, it was a terrible time” (girl 17)*. Or this boy (16), comments on his recollection of that time: *“It is*

strange really...I cannot tell you what happened and in what order... when what happened...I am sorry. It's unclear to me...it was just shitty – all together shitty!" probably this reflects the immense shock that the illness is to the families, and following the shock is a fuzzy-time fitting with Rolland's identification of transitions between phases. Uncertainty regards prognosis (is this fatal?) and process (what's next? What can be done?) and the nature of the illness itself (what will happen to her/him? What will become of us if?...)

Uncertainty in the chronic phase

In those stories describing the chronic phase (both from informants who are in that phase at the time of the interview and those who reconstruct it from the pre-terminal phase) major changes has occurred and there is a substantial effort made by the teenagers interviewed in order to re-establish new routines. Further, there is a feel of gaining some experiences with the illness, and even get into the habit of the illness: *"the worst was actually the second time she was hospitalized – then I knew what it meant – how much we would miss her and how terrible she would feel when she came home. And how grumpy my father would get" (girl 16)*. The parent may stop working, or go part-time during treatments and afterwards: more help with the practical sustainment of the household is needed from all members in the family (especially when the mother is ill, or in single parent households), and structures for that is negotiated, changed, settled upon, and then changed again. Also there is a common tendency in the material that the impact of the illness on everyday life, gradually sinks in, also as everyday life gradually/progressively changes and become more and more centered around the parents illness. Not knowing when and if the parent will get well again, stay sick, or die from his/her illness is a serious stressor identified by all informants as such, and by most informants this is even pointed out - as the worst part of living with illness in the family, during this phase. *"if she lives for 20 more years I would like to go travelling, but if she only has 3 years left - I don't feel like going away for 3 months. But no one can answer this question...it is so damned frustrating" (girl 17)*. Uncertainty in relation to the expected time left to live colors the plans and goals that the teenager set for him/herself, and it gives rise to immense emotional oscillations and internal dialogues: *"I think I am realistic about the threat. It is very serious, but her operation went well, so... but you never know...I have come to terms with that she is not going to be there when I become a mother. Maybe she can't even be there when I graduate...but that I hope she will...If I... I just can't loose her now. If it happened now...That I can't survive..." (Girl 16)*. This girl lives alone with her mother, who awaits a new kidney - it is evident within the time it takes to say the words, the girl experiences an ongoing internal dialogue with various possible outcome scenarios and their timeframes, reaching from cure to death, from second to decades. In some cases those scenarios are recognized as personified internal voices or I-positions i.e. the optimistic or hopeful

voice, and the dark or bad voice – whether or not these scenarios are named they seem to be competing for the person’s conviction, and they are highly dependent upon cues/signs from the outside depicted as events in the model. These could be a new message from the hospital and/or less well-defined occurrences (that the parent has not left the bed since morning, that the well parent bursts into tears.). The openness of outcome also is a source of faith and hope – and the chronic phase is also sometimes punctuated with times of optimism and relief: *“then there was a time, we were optimistic because my father responded well to the treatment, and I felt I could breathe again”*. A multitude of different time-frames are also relevant in relation to the microgenesis of everyday life of the teenager – and not just in relation to the further-into-the-future plans (like possibly going studying abroad, or going travelling, moving away from home etc.) as an ever present awareness of irreversibility of a time ending. *“In one way it is just another Monday, right... On the other hand it is also a Monday in the illness process, and it makes me acutely aware all the time, how to use time, and how we are to spent it together. In a way I both stress about the time we are maybe not going to have– and the time that we are actually having”* (girl 15). A common way of handling the uncertainty of time left with the parent, is to be conscious and firm in how to prioritize time and structuring the day in order to match the top priorities. This attempt to plan and structure things is also a strategy that proves vulnerable because it is hard to maintain and keep up plans, exactly because of all the unpredictable changes inherent in the illness process (and in life in general). Showing flexibility in relation to actions and choices is also common, always in relation to the given top-priority. *“I sometimes choose to go to a party, instead of just staying home always – but then if it proves boring or not that important anyway, I just change my mind and rush home, because I cannot waste my time on things that are unimportant”* (girl 19). Again in relation to the importance and acuteness of time left or possible cure - is the constant struggle with balancing tasks and responsibilities. *“I am always wrong in a way – or at least others think I am - I cannot manage it all. My teachers think assignments and school work is important and I have to make my assignments, but then I have to attend to obligations at home. When at home I know my friends are out doing stuff and they ask me to join and sometimes push me saying: come on, you can’t sit home always. It is just so very tiresome...I feel I am wrong no matter what I do”* (girl 19). At the core of the descriptions of reactions and challenges during the chronic phase is thus the tiresome and fearful uncertainty, exhaustion and conflicts around the impacts of the illness on the home, concern for family-members (especially younger siblings – but also the well parent), stress, fear and frustrations – punctuated by instances and times of good faith, hope, and optimism.

Uncertainty in the pre-terminal phase

That death is going to be the final outcome of the parents illness is almost impossible to relate to for the teenagers and that scenario is characterized by ambivalence, preparation, wait and dread. *"I am prepared for the worst now, and I have imagined how it will be – I have thought about how it will be like when the phone rings, and also about the funeral and that"* (girl 16). One informant serves here as a core-informant on the issue of uncertainty, since she knows the exact date for her father's death, because he is kept alive by a respirator that is going to be switched off three months after the interview. Uncertainty prevails even then, only in new ways, and she talks about it as "still unreal". The terminality of the situation around the illness is yet very prominent because the atmosphere and practices at home is completely taken over by the palliative team, with many professional health-care workers and nurses as integrated part of the home-environment. *"our home has become a hospital with a constant traffic of nurses and other health care personnel"* (girl 17). Most of the teenagers at this point have a top-priority of spending time at home, helping out, and struggle to hold on to and yet let go of their parent, and they feel that their life narrows down to basics: *"In my life there is just my dad who gets worse every day, my studies and my boyfriend – all the rest is like...I don't have room for my friends right now"* (girl 19). The time at home is described as almost unbearably tiresome, and often the dying parent is not-recognizable anymore – leaving the teenager and family in the midst of an ambivalent loss - some teenagers cannot stand being home a lot, or at all: *"When he dies I may regret that I did not spend enough time with him – but that is how it is. I cannot stand being close to him for too long. I need to also have fun and be happy – and that is impossible at home"*. Uncertainties related to the pre-terminal phase revolves around how fast it will go, and what it will be like, and fear of how much pain and agony and change in the parent it will bring about. But even though these uncertainties are massively present, the ideas about them are vague: *"Even though I know it – I cannot relate to it – at all"*. Also hope remains, but now (within a more limited horizon – despite for the dream of a miracle, that some admit too); in relation to more realistic wishes: that the final time will be bearable, that the parent remains him/herself to the end. A few informants have had this forewarning of death, a few times already and therefore find it difficult to believe that death is actually (ever) going to happen. *"I cannot really give into losing my father really, because what if he takes yet another year?"* Some informants admit to and describe the agony of bad conscience when reaching a point where they wish for their parent's death to come sooner than later.

Summing up

Although uncertainty is dealt with in various ways and, and every story is different from the other in important ways, we propose that the condition of uncertainty cuts across all phases of the illness of a parent. The events are different, and so are those emotions triggered in the oscillation– i.e. hope is more

prominent in the long haul, compared to in the pre-terminal phase, and dread and anxiety is more prominent in the pre-terminal phase, while confusion and chock is more prominent at the onset of the illness – but uncertainty and therefore also immense emotional volatility prevails even till the very end. Another common finding reflected in the model is that implication from the illness creates a tendency in the teenagers towards making firm splits between life-worlds: the private and the social life-world, as well as the home-zone and youth-life-zone. It seems as though these splits ensure the teenagers to gain a little control and sense of agency in everyday life and in relationships at home and with peers. But at the same time, these splits make them vulnerable to unavoidable intrusions between zones, as well as making them vulnerable to feelings of difference, social insecurity, isolation, bad conscience, and loneliness.

Emotional oscillation and distancing from peers

All informants describe emotional oscillations as a new and draining condition in their lives. Periods of hope and optimism is punctuated by periods of exhaustion and anxiety with next verdicts from the doctor coming up, new test results appearing, or the gradual realization of the parents increased incapacitation. Emotional oscillations are often, but not exclusively triggered by events strictly related to the illness. *“I usually get most depressed and sad when something else happens. Like if I quarrel with a friend, or I think a teacher of mine is unfair. Then it is just the last straw, then I feel I cannot take it anymore”* (boy 14). These mood-changes severely challenges participation in school life and relationships with peers and friends. *“It’s like I change all the time. I am definitely much more sensitive. Much easier to upset. I think people think I am grumpy all the time”* (girl 16). Putting up a happy face is easier towards peers and friends, because they tend “not to understand” and “Not know what to say” when confronted with hardships from every-day life experiences with an ill parent. The difference in scope, severity and kind of problems between themselves and their peers create a situation of de-identifying with same-agers; sometimes mixed with both envy and arrogance (as they feel much more mature). This leads to a profound feeling of distance to peers: *“I feel like I am in my own box - It is like I am in my box with illness and that, and they are in their box”*. Feeling different give rise to heightened social insecurity and social withdrawal, and in many cases friendships are broken and almost all informants report on how peers and friends have disappointed them; by not responding in caring ways, by avoiding them etc. Most teenagers report that, with time, they have found more effective ways to tell others about their situation and feelings, and they are more experienced in knowing who to tell what.

Creating a divide between a private and a social world

The tendency towards sharp divisions between a private world and social world is a general finding within the field of research on loss and grief, and is another way of conceptualizing the teenager's tendency to protect their parents from more worries and problems than they have already. This is a common finding among young carers, both as they appear in families with mental and or somatic illness (Trondsen 2011). This is linked to another common finding of role-reversals or "parentification of children" (Dyregrov 2012). These changing in dynamics within the family are to be recognized as complex adaptations that are fluctuating in their nature rather than static positionings (Ibid). As in one boys story – he is 14 at the time of the interview and looks back at the first years of his mother's illness. It took the doctors three years to diagnose her rare condition and to describe this time he says: *"My mum was seriously grumpy all the time - So one day at dinner, I snapped at her and my stepdad yelled at me: saying - "you just have to try harder" and at that point I just could not take it anymore. You try desperately not to show how sad you are, and at the end it just becomes a gigantic knot right under your heart and it just grows until it explodes... so I ran out to stay away. I wanted them to miss me, and feel sorry for me. When I came home I heard my mother crying upstairs. I heard her say: that now she has also failed in her role as a mother, and that she could not be a good parent for me and my brother anymore. It made me feel terrible – it was so sad. Because, I know that she did everything she could"...* In the interview material it becomes apparent that being caring, showing consideration for and protecting each other is a challenge in all the families at some points in time during the illness. Almost all teenagers recall times of neglect, lack of attention and consideration towards them, both from one or both their parents (and often also from the extended family – who forget to ask them how *they* are doing and only focus on the ill person) – and some react towards this with resentment and anger, followed by self-blame and bad conscience in the afterplay of quarrels - but most hide their disappointments and feelings of neglect. Hiding emotions is also true in relation to their fear of possibly losing the parent. *"I think I cannot talk about my fear of losing her – it's like I am giving up hope if I talk about it."* (girl 16). To some informants the demands of hiding their emotions and needs, or only show some of these create a distance between themselves and the family. Most teenagers understand why their needs cannot be the most important, but at the same time find it hard to reconcile their needs. They consider their private life-world as a way of caring best for everybody. Although some families (often through support from the extended network) are successful in maintaining usual compassion, openness and empathy for each other - everyone has to really make an effort to sustain these relations, as this girl (16) with a sick father explains: *"it is like we all need more from one another – but we all have less to give. In a way we just try very hard to remain ourselves"*.

Creating a divide between a family-life zone and a youth-life zone

Creating splits between a private and social life-world cuts across individual stories and also cuts across the categories of illness phases. Although this division both in relation to family and friends is ambivalent and troublesome, because it creates feelings of loneliness and social insecurity - it still minimizes conflicts and painful confrontations. Another important divide, regards the split between what we term a home/family zone (which relates to everything that has to do with the illness) and a youth-life-zone (everything else in their lives). As this boy (16) explains: *“Something I’ve thought a lot about in relation to getting my life up and running, is to get two worlds combined. Youth-life on the one hand, and the life with a sick parent on the other hand. You cannot really bring your sick father into your youth-life and one’s friends just really don’t know what’s going on”*. This split is difficult and demanding to maintain, because it often cannot stay complete, yet it is attractive because it gives a sense of control, as well as it affords some freedom from worries about the illness when with peers and at other places than home. To illustrate the difficulties of upholding the splits and the need to maintain them despite this difficulty another boy (14) explains: *“once I had forgotten my lunch-box and suddenly my mum turned up at school. The only thing I could think was just: Go home! Please just go home!”* His strong emotional reaction involved shame towards both his peers and his mother, who was clearly ill, but only there to try to help him, not realizing what a peculiar situation he felt it to be. Some teenagers describe the split as a great help to them, and some mention how the split set them free to indulge in fun and learning, when not home: *horse-back riding is like a get-away. Some place I can feel normal. I have not told it to anyone there* (girl 15). Only a few choose to bridge their home-zone and youth-life zone, and involve peers and teachers in their home situation– they prefer to deal with the challenge of intrusions of life-worlds, and then struggle with the mixing of spheres, also at times where they are not comfortable with it. In conclusion the many and various reactions to the many sided challenges and changes which parental somatic illness pose on the teenager’s life, we have tried to summarize in the suggested model: Uncertainty as organizing principle of action.

Possible implications for development

The tendency to making divisions in life-worlds we recognize as having important developmental significance, because teenage life usually is “all about” breaking boundaries between private life-worlds and obtaining intimacy and identification with peers. The reflexive efforts to establish close, and intimate relationships with peers, as well as the need to identify with peers and at the same time distancing themselves through acts of independence from the parents are all developmental tasks that are potentially skewed or distorted by the threatened loss caused by parental illness (Diareme et al. 2007: 102). The split between the home-zone and youth-life zone we also recognize as potentially skewing in relation to identity development. An important part of the separation process and relating to one’s parents from the new

position as a young person, is formed through mirroring family backgrounds and differences in relations to parents among teenage friends and it requires sharing different family experiences and relations. Finally, but not least, adolescence is characterized by an increased awareness and preoccupation with acquiring skills and competencies in preparation of adult life, incl. academic performance and in the arts/sports. The uncertainty of time left with the parent is causing a conflict of motives in relation to everyday choices regarding which activities to choose to attend, how often and for how long, so that the family-life zone comes in a competing position to youth-life activities (including school work). Ambitions on one's own behalf are thus potentially postponed due to the demands related to the illness (caring, house-keeping, concentration difficulties, absenteeism, depression). This means that this particular group of adolescents are at risk of missing out on crucial opportunity situations which allows for building access skills of relevance to their future life choices (Hundeide 2005). Splitting up life-worlds may be a necessary strategy for surviving the hardships of living in fear of losing a parent, but this mechanism, can become maladaptive if it is not properly understood by the teenagers themselves, their peers, teachers, and counselors. In light of this, the growing body of scientific studies both describing the situation from the point of view of the children, as well as studies evaluating effective family intervention strategies and disseminating results to health-care personal, teachers, peers and parents is a most needed development within this field.

References

- Birenbaum L.K., Yancey D.Z., Phillips, D.S., Chand N., Huster, G. (1999). School-Age Children's and Adolescents' Adjustment When a Parent Has Cancer. *Oncology Nursing Forum*, 26 (10); 1639-1645.
- Bugge, K. E.; Helseth, S., Darbyshire, P. (2008). Children's experiences of participation in a family support program when their parent has incurable cancer. *Cancer Nursing*, vol. 31. No. 6. Pp. 426-434.
- Boss, P. (1999). *Ambiguous Loss*. Cambridge, MA: Harvard University Press.
- Christ, G. H.; Siegel, K. Christ, A. (2002). Adolescent grief "it never really hit me...until it actually happened". *JAMA*, 11, vol. 288, no. 10. Pp. 1269-1278.
- Christ, G. H., Siegel, K., Sperber, D. (1994), impact of parental terminal cancer on adolescents. *American Journal of Orthopsychiatry*, 64: 604-613.
- Diareme, S. Tsiantis, J. Romer, G. Tsalamaniotis, E., Anazontzi, S. Paliokosta, E., Kolaitis, G. (2007). Mental health support for children of parents with somatic illness: a review of the theory and intervention concepts. *Families, Systems and Health* (2007). Vol. 25, no. 1. 98-118.

- Dyregrov, K. (2012). Når foreldre har alvorlig kreftsygdom – eller dør av den. Haugland, B. S., Ytterhus, B., Dyregrov, K. (eds.). *Barn som pårørende*. Abtrakt Forlag. Pp. 44-66.
- Engelbrekt, P. (2005). Netværkets centrale betydning når forældre rammes af alvorlig sygdom. *Omsorg-Nordisk tidsskrift for palliativ medicin*, 22(4), 2005. pp 25-29.
- Gabiak, B. R.; Bender, C.M.; Puskar, K. R. (2007). The impact of parental cancer on the adolescent: an analysis of the literature. *Psycho-Oncology*, 16, pp. 127-137.
- Grant, K.E., B. E. Compas (1995) *Stress and anxious-depressed symptoms among adolescents: searching for mechanisms of risk*. *Journal of Consulting and Clinical Psychology* 63: 1015-1021.
- Hundeide, K. Socio-cultural tracks of development, opportunity situations and access skills, *Culture & Psychology*, 2005; vol. 11; 241-261. Sage Publications.
- Kvale, S., Brinkmann, S. (2009). *InterViews- learning the Craft of Qualitative Interviewing*, 2nd ed. Sage Publications.
- Pattison, E. M. (1978). The living-dying process. In C. A: Garfield (ed). *Psychosocial care of the dying patient*. New York. McGraw-Hill pp. 133-168.
- Rando, Therese (1986). A comprehensive analysis of anticipatory grief: perspectives, processes, promises, and problems. In, Rando T. (Ed.) *Loss and anticipatory grief*. Lexington books. P. 3-39.
- Rolland, J. S. (1999). Parental illness and disability: a family systems framework. *Journal of family therapy* (1999) 21: 242-266.
- Siegel, K. Mesagno, F. P. Karus, D. Christ, G, Banks, K. & Moynihan, R. (1992). Psychosocial Adjustment of children with a terminally ill parent. *Journal of American acad. Child and adolescent psychiatry*. 31. 2 march.
- Thastum, M., Johansen, MB, Gubba, K. Olesen, L.B., Romer, G. (2008). Coping, social relations, and communication: a qualitative exploratory study of children of parents with cancer. *Clin Child Psychol Psychiatry*. 2008 Jan, 13(1) pp. 123-38.
- Trondsen, M. (2011). Living with a mentally ill parent: exploring adolescents' experiences and perspectives. *Qualitative Health Research*, 22(2) pp 174-188.
- Valsiner, J. (1997) *Culture and the development of children's actions - a cultural-historical theory of developmental psychology*. John Wiley and Sons.
- Visser, A., Huizinga, G. A., Van der Graaf, W., Hoekstra, H.J., Hoekstra-Weebers, J.E:H.M. (2004). The impact of parental cancer on children and the family: a review of the literature. *Cancer Treatment Review*, 30, pp. 683-694.

