From Department of Neurobiology, Care Sciences and Society
Karolinska Institutet, Stockholm, Sweden

UPHOLDING FAMILY RELATIONSHIPS IN A CONTEXT OF INCREASING AWARENESS OF PARENTAL ILLNESS

Charlotte Oja

Stockholm 2021

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Published by Karolinska Institutet.
Printed by Universitetsservice US-AB, 2021

ISBN 978-91-8016-252-4
Cover illustration: Original aquarelle painting by Karolina Bjernby Dufva: The wave of awareness

Upholding family relationships in a context of increasing awareness of parental illness

THESIS FOR DOCTORAL DEGREE (Ph.D.)

By

Charlotte Oja

The thesis will be defended in public at Karolinska Institutet, Huddinge, on 4 June 2021 at 1:00 pm.

Principal Supervisor:
Professor Solvig Ekblad
Karolinska Institutet
Department of Learning, Informatics, Management and Ethics
Cultural Medicine

Co-supervisors:
Professor Jörgen Månsson
University of Gothenburg
Department of Public Health and Community Medicine/Primary Health Care
Division of Medicine

Associate Professor Anna Nager
Karolinska Institutet
Department of Neurobiology, Care Sciences and Society
Division of Family Medicine and Primary Care

Tobias Edbom PhD
National Board of Health and Welfare
Department of Analysis

Opponent:
Associate Professor Steven Lucas
Uppsala University
Department of Women's and Children's Health

Examination Board:
Professor Kjerstin Almqvist
Karlstad University
Department of Social and Psychological Studies

Associate Professor Hans Thulesius
Linnaeus University
Department of Medicine and Optometry
Division of Health and Life Sciences

Associate Professor Bledar Daka
University of Gothenburg
School of Public Health and Community Medicine
Institute of Medicine
Sahlgrenska Academy

This work is with loving
appreciation dedicated to
my mother and father,
my teachers,
my husband and children,
and my patients.

“No man can attain his true station except through his justice.
No power can exist except through unity.
No welfare and no well-being can be attained except through consultation.”
(Bahá’u’lláh, 1817-1892)

POPULAR SCIENCE SUMMARY OF THE THESIS

Children are affected when a parent is ill and parental illness can therefore be a risk factor for the child’s health. Health care professionals are legally bound to consider children’s needs to receive information, advice, and support about their parent’s illness when the parent is seriously physically or mentally ill or dies. Psychological and pedagogical interventions have been created in the fields of psychiatry that include parental alcohol and substance abuse, and cancer- and HIV care. However, a vast majority of patients in Sweden are treated in primary health care where these methods are not applied. It is therefore unknown whether parental illness within primary health care creates a challenge and risk for the children. It is also unknown how the children and parents deal with the situation and what strategies they use or should apply.

To explore the understanding and interaction of parents and children, interviews were conducted with 32 parents and 23 of their children in three primary health care clinics. The parents had on average been on sick leave for a year.

This thesis explores this new theme through analysis of interviews with children and their parents, and of the literature. The literature shows that interventions affect the child’s emotional state. Further, children and parents have a joint need not only to understand the illness and talk about it but also to find tools and strategies to handle the situation and the emotions that come with it. Parents undergoing interventions appreciate their increased understanding of their own child, the positive changes they have observed in their own children’s behaviour, and the experience of knowing their child is at ease.

Analysis of the interviews using the grounded theory method revealed that both parents and children, by upholding family relationships, at the same time sustain family equilibrium. The child feels burdened and lonely when the parent is ill and wants the parent to talk about the illness and the effects it has. The parent is aware that the child knows that the parent is ill and that the child wishes the parent to talk; but the parent often feels incapable of doing so.

From these findings a grounded theory was developed, conceptualizing what it takes to uphold family relationships in a context of increasing awareness of parental illness. To be able to speak about the illness the parent needs to be able to handle the awareness about the illness he or she shares with the child. And to handle this common awareness context the parent must comprehend both the illness and the child’s needs. Six different awareness contexts are proposed – closed, concealed, suspicious, conflicted, mutual pretence and open. Added to this is an understanding of how parents manage, or often fail to manage, to move between the concepts of the common awareness towards open awareness.

Both parents and children wish for support from primary health care in the learning process that is often needed. By using the theory presented in this thesis professionals can find out in which awareness context regarding the illness their patient stands together with the child. From there the appropriate steps can be taken to give the parent much-needed support. With better understanding of the illness and the child’s needs the parent gains a better capacity to communicate. This in turn reduces family tension and provides the child with a better situation in which to grow and develop.

POPULÄRVETENSKAPLIG SAMMANFATTNING

Barn påverkas då deras förälder är sjuk och därmed kan förälderns sjukdom vara en riskfaktor för även barnets hälsa. Enligt lag ska sjukvårdspersonal beakta barnets behov av information, råd och stöd när deras förälder är allvarligt psykiskt eller fysiskt sjuk, eller dör. Pedagogiska och psykologiska program har också utvecklats inom psykiatrin, beroendevården och cancervården för att tillfredsälla dessa behov hos barn. Men det stora flertalet patienter i Sverige behandlas inom primärvården, och här saknas kunskap om hur stort problem föräldrars ohälsa utgör för barnens hälsa. Det är också okänt hur barn och föräldrar handskas med sin situation och vilka strategier de använder, eller bör använda, för att komma till rätta med situationen.

I syfte att utforska barns och föräldrars egen förståelse av sin situation samt interaktionen mellan förälder och barn genomfördes, inom ramen för detta avhandlingsarbete, intervjuer med 32 föräldrar och 23 av deras barn på tre vårdcentraler. Föräldrarna hade i genomsnitt varit sjukskrivna i ett år.

Svaren analyserades parallellt med en systematisk översiktsanalys av tillgänglig vetenskaplig litteratur på området. Sammanställningen av intervjuerna och litteraturstudierna visar att interventioner för barn med sjuka föräldrar har positiv effekt på barnets känslomässiga tillstånd. Det framkommer att föräldrar och barn har ett gemensamt övergripande behov av att inte bara förstå och börja kommunicera om förälderns sjukdom utan också få bättre strategier för att kunna hantera situationen och sina egna negativa känslor kring den. Det framkommer även att föräldrarna som deltagit i interventioner värdesätter sin ökade förståelse för sina egna barn, de positiva förändringar de ser i sina egna barns beteende och att få se sina barn tillfreds.

Analysen av intervjuerna, genom att använda metoden grundad teori, visar att både föräldrars och barns huvudsakliga utmaning när föräldrar är sjuka är att försöka upprätthålla familjens relationella jämvikt. Barnet känner sig tyngt och ensamt när dess förälder är sjuk och vill att föräldern ska berätta om sjukdomen och hur den påverkar föräldern. Föräldern å sin sida är medveten om att barnet känner av sjukdomssituationen och att barnet vill att föräldern ska berätta. Men föräldern känner sig ofta oförmögen att göra det.

På basis av detta utvecklades, inom ramen för avhandlingen, en grundad teori som fångar in vad som behövs för att upprätthålla en bra familjerelation i ett sammanhang av gradvis ökad medvetenhet om förälderns sjukdom. För att kunna berätta behöver föräldern kunna hantera den gemensamma medvetenhet som barnet och föräldern har kring förälderns sjukdom. Och för att kunna hantera den gemensamma medvetenheten behöver föräldern också förstå sin egen sjukdom samt barnets behov.

Sex olika faser av medvetenhet kring förälderns sjukdom föreslås - stängd, dold, misstänksam, konfliktfylld, ömsesidigt lotsande och öppet. Till detta kopplas förståelse för hur föräldrar och barn förflyttar sig, eller ofta misslyckas med att förflytta sig mellan dessa faser, fram till öppen medvetenhet.

Både föräldrar och barn önskar att primärvården stödjer dem i den lärandeprocess som ofta behövs. Genom att använda denna teori kan sjukvårdspersonal identifiera i vilken medvetandefas föräldern och barnet befinner sig i kring förälderns sjukdom och därmed bättre kunna bistå föräldern med passande steg. Genom en förbättrad förståelse om sin sjukdom och sitt barns behov får föräldern bättre möjlighet att berätta för sitt barn. Därmed finns möjlighet för att den känslomässiga spänningen i familjen minskar och att barnet får bättre förutsättningar för att utvecklas hälsosamt.

ABSTRACT

Background

Children are affected when parents are ill and health care professionals are bound by law to consider children's need for information on their parent's illness. Effective interventions are available in settings other than primary health care, and possibilities seen by GPs and families have been described previously. Most patients in Sweden are treated in primary health care. It is suspected that parental health problems treated in primary care create a challenge and risk for the children. It is unknown how children and parents negotiate this situation and what strategies they use.

Aim

The overall aim was to conceptualize the situation of ill parents and their children in primary health care, as a contribution towards the long-term goal of developing suitable and sustainable interventions for children as next of kin in primary care.

Methods

Analysis of interviews with 32 parents and 23 of their children in three primary health care clinics using grounded theory method resulted in a conceptualization of (i) how these children view their situation (Study I) and (ii) a theory on the processes and typologies of upholding family relationships from the perspective of their parents (Study III). A systematic review exploring interventions for children of ill parents in all health care settings globally resulted in a full overview of the literature and, via content analysis, a resulting summary of what children and parents find helpful in interventions (Study II). All three studies were analytically integrated in this thesis.

Results

Analysis of the interviews revealed that children feel burdened and lonely when their parents are ill (paper 1) and wish their parent to reveal (paper 3). Parents are aware that their children know they are ill and wish their parents to reveal, but often feel incapable to do so. A Grounded Theory conceptualizing what it takes to uphold family relationships in a context of increasing awareness of parental illness (paper 3) was developed. Six different awareness contexts are posed (closed, concealed, suspicious, conflicted, mutual pretence and open) and how parents manage, or often fail to manage them, are conceptualized. The theory hypothesises that to reveal the parent needs to manage their common awareness context about the illness. And to manage their common awareness context the parent must comprehend the illness and the child needs. Parents and children wish primary health care to support the often-needed learning processes. (Study 1 and 3).

Thirty-two studies conducted in mental health (n=22), cancer care (n=6) and HIV care (n=4) were analysed in a systematic literature review. The *quantitative* studies showed a small-to-moderate effect on the health of the child. Systematic content analysis of *qualitative* results from mental health and cancer care generated new data concerning what both children and parents found useful in interventions (increased knowledge, improved communication, improved coping strategies and better capacity to handle negative feelings) and additional benefits perceived by the parents (observed changes in their children's behaviour, increased understanding of their own child and enjoyment of the child's respite).

A synergy arises from the three papers that comprise this study to reveal that (i) the chronically ill parent and child share the same main concern of sustaining family equilibrium; (ii) explains how their interactions can create more positive or more negative awareness contexts about parental illness and (iii) elaborates how a family can be supported to shift from one context to another.

Conclusions

This thesis impacted the theoretical literature on children as next of kin in primarily two ways, by making it clear that the theme child as next of kin is central, but previously overlooked, in primary health care and by contributing a theory of the detailed interactions of parent and child, showing how they manage or fail to manage their common awareness context about the parental illness.

For practise this has implications. The study points out the current neglect of child as next of kin in primary health care and highlights ways in which to apply the intention of the law. It provides a conceptual framework which can be used to create an outline of suitable clinical actions, inform management of clinical reality, increase professional understanding of patients and increase parents understanding of how they can manage their awareness context with their children when ill.

Key words

Child of impaired parents; primary health care; sick leave; parent-child relations; family health, qualitative research; health promotion.

LIST OF SCIENTIFIC PAPERS

I. Charlotte Oja, Tobias Edbom, Anna Nager, Jörgen Månsson & Solvig Ekblad (2018): Making life work for both themselves and their parents alone- how children aged 11–16 view themselves in relation to their chronically ill parents in a primary health care setting, International Journal of Adolescence and Youth, DOI: 10.1080/02673843.2018.1548360

II. Oja C, Edbom T, Nager A, Månsson J, Ekblad S (2020) Informing children of their parent's illness: A systematic review of intervention programs with child outcomes in all health care settings globally from inception to 2019. PLoS ONE 15(5): e0233696. https://doi.org/10.1371/journal.pone.0233696

III. Oja C, Edbom T, Nager A, Månsson J, Ekblad S (2021) Awareness of parental illness: a grounded theory of upholding family equilibrium in parents on long-term sick-leave in primary health care. Scandinavian Journal of Primary Health Care, accepted and in print.

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PROLOGUE

Before the privilege of embarking on this scientific learning and research process my identity was that of a clinical physician. As I was interested in people and systems and believed in the power of coherence, I was drawn to family medicine. When working on a clinical problem in family medicine potentially anything can be relevant, and nothing can automatically be excluded. For fifteen years I worked as a family medicine specialist of at the same clinic and followed patients and families as they evolved over time. Gradually a longing to deepen in some topic grew and for a year I pondered what topic to explore.

Then, on an ordinary day in an initially ordinary patient visit, I had an extraordinary experience. A school-aged child was booked for prolonged cough. The mother was my patient on sick leave for pain and exhaustion. We talked about the cough and I examined the child and finding nothing alarming, we decided to wait and give nature a chance. As the two were ready to leave the mother said to her child. – "*This is my doctor who is helping me with my health*." We had a brief conversation about the mother's health and treatment and, contented, they left. I remained in my chair happy and bewildered. What was so powerful and liberating in this brief simple exchange? This is not how it normally happens. I became fascinated and had to figure out what *had* happened. What made this different? The parent child relationship when parents are chronically ill, thus became the focus of my PhD studies.

ABBREVIATIONS AND DEFINITIONS OF CENTRAL CONCEPTS

Child	child (age 18 or younger) of impaired parents/child as next of kin/child of chronically ill parents
Parent	ill or impaired parent/person doing parenting
PHC	Primary Health Care
FM	Family Medicine
GT	Grounded Theory

1 INTRODUCTION

This introduction gives an overview of the facts and dynamics of the setting in which children as next of kin in primary health care plays out: the goals of sustainable health for future generations, of sustainable family medicine and coherent rational thinking and the reality of increasing burden of chronic symptoms, weakening family medicine and intransigent and dichotomizing thinking.

1.1 THE HEALTH GOAL FOR FUTURE GENERATIONS VERSUS THE REALITY OF AN INCREASING SYMPTOM BURDEN

1.1.1 Goal of sustainable health versus increasing symptom burden

According to the Charter of the World Health Organization (WHO) (1) and to common understanding, health is "a state of complete physical and social wellbeing, and not merely the absence of disease or infirmity. The enjoyment of the highest attainable standards of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, or economic or social condition". The WHO further stresses "the importance of improving maternal and child health and welfare, as well as progress in the field of mental health", stating that "mental health is the foundation for the well-being and effective functioning of individuals. It is more than the absence of a mental disorder; it is the ability to think, learn, and understand one's emotions and the reactions of others. Mental health is a state of balance, both within and with the environment". The third global goal of the UN's 2030 Agenda for Sustainable Development challenges us to "ensure healthy lives and promote well-being for all at all ages" (2). The United Nations Convention on the Rights of the Child (3), which became law in Sweden on 1 January 2020, states that children should enjoy rights including the right to be listened to, and should be given special protection, opportunities and facilities.

Health measured in hard endpoints such as life expectancy is increasing globally (4). However, there is a disturbing health discrepancy between different population groups. In Stockholm, there is a difference of several years in life expectancy between highly educated people in a northern district and those with low education in a southern district. This disparity has recently been manifested in increased mortality in COVID-19 in low-income neighbourhoods (5). Stress-related symptoms are high among schoolchildren, youth, and adults in Sweden. In 2020 there were 159 000 ongoing sick leave cases, 103 000 women and 56 000 men. Benefits were given mostly for psychiatric diagnoses (51%) including stress (22%), injuries (13%) and musculoskeletal illness (10%) (6). Seriously ill patients in primary health care (PHC) have diverse and multiple illnesses often including a combination of mental and somatic symptoms as well as social and economic risk factors. The severity of the illness is usually not defined by the diagnosis or mortality, but rather by a lack of everyday function over an extended period.

1.1.2 Parent-child relations as a factor for and against sustainable child health

A child’s attachment and relationship to his or her primary caregiver, here called parent, is crucial for the child’s development and health. Early parent-child attachment (7) is a decisive factor for the child’s current and future health. Parents provide the child with experience and populate the environments that guide her or his development. They are thereby essential to child health. Parenting is expressed in cognition and practice (8). Generally, a child that mostly experiences safe positive interactions is likely to thrive. Conversely, when the child often has negative experience her or his development suffers. The association of parenting and child development has been repeatedly shown, measuring different specific negative impacts and outcomes. Thus a meta-analysis (9) shows the association between children’s exposure to intimate partner violence and child externalizing, internalizing, and total adjustment problems. A Finnish study shows that severe violent acts directed towards the child were self-reported by 6% of the mothers. It was also found that corporal punishment experienced by the mother as a child or used by her as a method of discipline, and work- or family-related stress and lack of help in dealing with parenting problems strongly increased the likelihood of severe violent acts towards the child (10). Adolescence is a period of rapid growth and can be challenging. The parenting styles of mother and father are associated with the adjustment of their teenager (11).

1.1.3 Socio-economic factors; cultural diversity

Socio-economic factors are strongly associated with health outcomes. Structural determinants and conditions of daily life are the social determinants of health. Current inequity in structural determinants and conditions of daily life causes health inequity within and between countries and neighbourhoods (12). For instance, the risk for a child to be admitted to hospital in Sweden has a social gradient of over 40%. Thus, children with the highest social status are 40% less likely to be admitted to hospital than those with the lowest. The corresponding social gradient for receiving a mental health or respiratory diagnosis is around 70%. The risk of an individual child’s being admitted to hospital for a mental health diagnosis is 37% higher during a year when that child’s family is receiving economic welfare than during other years in that child’s life (13).

Sweden is historically a country of emigration due to poverty and oppression. In the twentieth century, Sweden gradually changed to a country of immigration. At present 20% of the county’s population is foreign born (14). This group of foreign-born individuals is diverse, and the life conditions of children of foreign-born parents vary. Ill health in children is much more strongly associated with social and economic vulnerability than with parents’ birth country (13).

1.1.4 Transgenerational transferal of illness

Parental illness can, in a broad sense, be a risk factor for current and future ill health in the children. A systematic review (15) found an association between depression in mothers and depression in their school-aged children. Paths of transmission include genetic factors, shared social and economic factors and the effect of the illness on the parenting function (16). Based on numerous relevant theoretical reviews of child psychological development, Diareme (17) presents children's developmental issues related to somatic parental illness as follows:

Infancy: Separation from parent(s) and inconsistent physical and emotional care by parent(s).

Toddlerhood: Separation from parent(s) (experienced as abandonment or punishment) and inconsistent provision of attention and limit setting.

Preschool: Magical thinking of having caused the parent's illness, illness experienced as punishment, and fun and play perceived as inappropriate.

Latency: Irrational fear of causing or exacerbating parent's illness and associated guilt, somatic complaints (due to age-expected identification with ill parent), fear of losing the healthy parent (due to age-expected dependency on parents), guilt for having fun, and feeling unimportant.

Adolescence: Guilt or ambivalence about desire for independence (due to age-expected need for autonomy), somatic complaints (due to age-expected concerns with body image and health identity formation issues), shame about ill parent (due to age-expected need for peer acceptance), resentment of increased responsibilities at home (due to age-expected need for independent activities), negligence or compromise of own growth and autonomy (due to age-expected guilt for wanting to separate from ill parent) (17).

At any age, the child can respond to parental low mood in different ways, functional or dysfunctional. Four patterns of child response have been discovered: active empathy, emotional over-involvement, indifference, and avoidance. The emotional over-involvement and avoidance groups reportedly have more depressive and externalized symptoms than the other two groups (18).

1.1.5 Children of impaired parents; and interventions

Parental illness is sometimes a defining feature of a child's everyday life. There is no published data on the prevalence of different levels of parental dysfunction due to illness in Sweden. However, reports indicate that this affects many children. One report describing children of parents hospitalized for at least one week at least once during the child's childhood (19) concluded that this affects 25.7% of children in Sweden (12.6% somatic illness, 5.7% psychiatric illness, 3.4% death of parent, 2.5% alcohol dependence and 1.5% dependence on narcotics). Many more children are assumed to have parents with illnesses not requiring hospitalization for one week or more. There is yet no published calculation of how many children in Sweden are affected by parental chronic illness in a PHC setting.

Recognition that children in families affected by parental illness run a greater risk of illness and other poor life outcomes has resulted in the creation of a variety of psycho-educational interventions (20-24) to reduce the negative effects of the parental illness on the children and to support children's healthy development.

1.1.6 Law and policy regarding children as next of kin

From a perspective of law and policy, including the third of the global goals of the UN's 2030 Agenda for Sustainable Development (2) and the United Nations Convention on the Rights of the Child (3), there are impelling reasons to focus on how to better protect the health of growing children. Furthermore, some national regulations guide health care staff treating adult patients to attend to the needs of these patients' children. In Sweden health care professionals are by law (25) required to take into account the needs of their patients children for information, advice and support. This applies when the parents are seriously mentally or physically ill, have an addictive disorder or died. Similar legislation exists in Denmark (26), Finland (27) and Norway (28). Despite efforts to implement these laws health care staff are still often unaware of the law and have not received any specific training to meet its requirement. In cancer care, patients are often offered contact with a councillor, but few clinics have specific focus on children as next of kin. When focus and staff training have taken place, such as for instance using the Beadslees family intervention (29) in psychiatry, few interventions have so far been delivered. A study in 2018 from adult psychiatry show that one-fourth of the patients who were parents received child-focused interventions. Out of these 30.7% were involved in interagency collaboration as compared to 7.7% without child-focused interventions (30). Still, a report concludes that the number of family interventions performed by those trained is still low (31).

1.2 THE GOAL OF SUSTAINABLE FAMILY MEDICINE/PRIMARY HEALTH CARE VERSUS THE REALITY OF SIGNS OF WEAKENING AND DISINTEGRATION

1.2.1 Family medicine and primary health care

Efforts to define family medicine globally find that unifying components include comprehensive care throughout life, the management of the common illnesses of that particular community, socially accountable responsiveness to local need, adaptation of existing health infrastructure, and the ongoing development of the skills required to succeed in that role, always grounded in the relationships of care (32).

Primary health care (PHC) is often used similarly, for instance as defined in the Medical Subject Heading (MeSH) as "Care which provides integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community". PHC also refers to the care being the primary contact for patients when seeking help. If necessary, the patient can be referred to secondary or tertiary care. After investigation and sometimes treatment in secondary or tertiary care, the patient is often referred back to PHC for continued management.

1.2.2 Disintegration in relation to other actors

Challenges in PHC in Sweden to develop a coordinated, modern, equal, accessible, and effective health care with a focus on PHC have recently resulted in a governmental reform entitled ‘good and close care’: in Swedish *god och nära vård* (33). The current challenges include problems in retaining competent staff, which make relational continuity and trust between patient and professional difficult. The main target of the reform is to point out that PHC is responsible for first-line care for both physical and mental ill health. The reform suggests that PHC should work with mental health according to the “Correct support of mental health” model, which includes principles and work methods to improve individual care and to better serve needs on population level.

1.3 THE GOAL OF COHESIVE RATIONAL THINKING IN A DISCOURSE SHOWING SIGNS OF INTRANSIGENT AND DICHOTOMIZING THINKING

1.3.1 Cohesive rational thinking as a goal

When working in family medicine a systemic perspective comes naturally. The general systems theory (34) states that it is necessary to study not only parts and processes in isolation, but also to solve the decisive problems found in the organisation and order unifying them and resulting from the dynamic interaction of parts. Systemic thinking has been applied to understand systems varying from climate change to mental health. In family therapy it has developed into an emphasis on the relationship between the symptom bearer and significant others in the present (35).

To orientate and function in family medicine one needs to trust that credible sources of knowledge are available. The credible main sources of knowledge used are science, surrounding professionals, and the patient. It is essential that the clinical GP has access to relevant science. When science is of poor quality or does not address questions relevant to the setting, its credibility in that setting is decreased. When credible colleagues are not accessible the learning process will slow down, and medical investigation and treatment lose credibility in the eye of the patient. In addition, the patient is the main source of relevant information on symptoms and their influence on his or her life. For the process of medical investigation and treatment to function, the professionals need to view the patient as credible and the patient needs to view professional as credible.

Medical training often includes training in patient-centred care. The concept was first used by Balint (35) who proposed that doctors in addition to discovering a localizable illness also have to examine the whole person in order to form an overall diagnosis, including everything the doctor knows and understands about the patient and in fact understanding the patient as a unique human-being. According to one framework (36), five distinct dimensions of patient-centred care have been identified:

1. A biopsychosocial perspective including consideration of social and psychological factors

2. The patient-as-person including understanding what the illness means to each individual patient
3. The sharing of power and responsibility including sensitivity to patients' preferences for information and shared decision-making
4. The therapeutic alliance, meaning the development of common therapeutic goals, and
5. The enhancement of the personal bond between doctor and patient and the 'doctor-as-person' awareness of the influence of the doctor's personal qualities and subjectivity on the practice of medicine.

It is recognized that clinical practice often is not patient-centred even though professionals have been trained to work in a patient centred way (37).

1.3.2 Family-centred care in a discourse of intransigent and dichotomising thinking about child and parent

Family-centred care simply means respect for the family setting of the individual, whatever their current setting or age. In the present work, terms will be used in the following ways. *Parents* are persons functioning as natural, adoptive, or substitute parents. *Nuclear families* are composed of spouses and their children, and by *family* is meant a social group consisting of parents or parent substitutes and children. *Parenting* is when a natural or substitute parent performs the parent role by giving the child care, nurture and protection. The parent supports the child by exercising authority and through consistent, emphatic, appropriate behaviour in response to her or his needs. The parent's responsivity and qualities of exemplary behaviour are here emphasised.

1.3.2.1 The perspective of the child and adults having a child perspective

Understanding of child and childhood has evolved with society over time. In this thesis, it is necessary to simply point out that it must always be remembered that *all* individuals have an unassailable right to their own experience, perspective, and point of view. The child needs to be encouraged to share their experience and point of view. As the child grows, the capacity for self-expression increases and agency develops. Thus, the child's perspective is crucial. From this understanding it was decided to begin the present study with the analysis of interviews from the perspective of the interviewed children.

Parents and society have always recognised that infants and children need special protection and support to develop their innate capacity. This is achieved by adults taking responsibility for their children's needs. When this happens, the adults are acting from a child perspective. The first and main persons responsible for the wellbeing of children are indeed the parents. In Swedish law, this is currently codified in the Parental Code of 1949, *föräldrabalken* as "the child has a right to care, safety and a good education. The parents or guardians are responsible for the personal situation of the child, and for satisfying the needs of care, safety, and education of the child. The parents or guardians are also responsible to provide the needed supervision of the child and monitor that the child gets a satisfactory livelihood and education" (author's translation) (38). Parents are charged with a substantial task, meriting respect, and support from others.

1.3.2.2 Recent focus on the rights of the child

Recognizing that children do not always have parents who can satisfactorily be "responsible for the personal situation of the child, and for satisfying the needs of care, safety, and education of the child", the community tries to add support by law, policy and services.

As mentioned before, the Health Care Act specifies that the child has a right to health and health care services; also that health care personnel are required to give information, advice and support to under-aged children whose parents are seriously psychiatrically or physically ill, have an addictive disorder (including gambling), or have died (25). The Convention on the Rights of the Child (3) also specifies that the child has a right to information, especially material aimed to improve his or her social, spiritual and moral wellbeing and physical and mental health.

Child-welfare systems, that is, organized efforts by the community to improve the health and well-being of the child, are also in place. The Social Services Act *socialtjänstlagen* specifies that decisions or other activities related to care or treatment of children should be decided by what is in the best interest of the child (39). The Act also regulates what child welfare should do when parents appear not to be fulfilling their task. The task of citizens and professionals meeting children is to report their worry for an individual child.

The Social Services Act governs the field of maltreated children/*barn som far illa*. The Health Care act govern the field of children as next of kin/*barn som anhöriga*. When comparing the two acts, it becomes clear that both aim to protect the health and wellbeing of the child. From a health-care perspective, parents are initially assumed to fulfil their broad parenting task reasonably well. When there are signs that the parent is unable to do so health-care professionals must report their concern to social welfare and this organisation takes over the responsibility to investigate and possibly act. However, health care is alone responsible for the aspect of child wellbeing concerning information and support regarding the parental illness. Parents usually wish to cooperate with others for their child's wellbeing. When they do not cooperate, child welfare is empowered to act against their will. There is no such possibility for health care when attempting to give the child access to information about the parents' illness.

As this is a complex area of relationships, rights and responsibilities, there is a natural but unfortunate tendency in public discourse towards simplified dichotomised thinking. This results in putting different important aspects in opposition to each other, instead of striving to understand how the different aspects are parts of one whole. Examples of such unspoken underlying dichotomies in clinical practice and research concerning parents and children are:

- Should we care for the parent or for the child?
- Should we act for the child against the will of the parent?

- Should we do research and pursue policy as well-willing adults with a child perspective, or should we strive to capture the child's perspective?

It seems more appropriate and fruitful to try first to understand how the rights and best interests of children and their parents can be understood together.

2 INITIAL LITERATURE REVIEW

An initial and limited literature review showed that that it was not easy to find many well-conducted studies of children as next of kin.

The review showed that a dependent child of physically and mentally ill parents is affected in different ways, including biological, psychological, social, and existential. Narrowing the focus to the psychological and social effects on the child indicated that children of ill parents run a higher risk of themselves falling mentally ill. This has been well studied in the case of maternal depression (15, 40) and models for the transmission have been suggested (16, 41). Naturally, the degree of parental dysfunction matters (42) and the active compensation of the father decreases the risk (43). Non-depressed parents perform more routines, report better coping with parenting, behave significantly less punitively and need less social support than depressed parents do (44).The child's depression often goes undetected (45). Adolescent mental health problems are common, but not inevitable, even when parental depression is severe and recurrent (46). Interventions decrease the risk of the child receiving new diagnoses (47).

Further, being a child of an impaired parent might influence the child's social development. For instance, adverse childhood experience of different kinds, (parental death, parental substance abuse and psychiatric disorder, substantial parental criminality, household public assistance, parental disability pension and child welfare intervention) all, especially in combination, increase the risk of the child's early midlife retirement (48).

Children are emotionally attached to their parent, and will struggle to understand themselves by understanding their parent (7). Models have been proposed for understanding dysfunctional psychological mother-child relationships by merging developmental psychopathology, behaviour and trauma literature (49). One key to reducing depressive symptoms and enhancing adaptive functioning among middle-school children is to build their resourcefulness (50).

From this initial literature review it became evident that there is very little knowledge about children as next of kin in a PHC setting. To ensure not missing important scientific work and in order to make a full synthesis of the effects of all interventions aimed at lessening the impact of parental illness on the child, a systematic literature review of intervention was conducted. The results are reported under Results, section 5.2.

3 RESEARCH AIM

The overall aim of the work reported in this thesis was to conceptualize the situation of ill parents and their children in primary health care, as a contribution to the long-term goal of developing suitable interventions for children as next of kin in PHC. This was achieved in three sub-studies, addressing the following specific aims:

- Study I sought to understand children’s main concern and strategies concerning their parents’ illness and their wish for support in PHC
- Study II sought to systematically review and analyse existing interventions for children as next of kin in all health care settings to synthesise learning
- Study III sought to understand parents’ main concern and strategies regarding the effects of their chronic illness on their own children’s health and wellbeing and their wish for support from PHC

4 MATERIALS AND METHODS

4.1 OVERVIEW OF STUDIES

To assist the reader Table 1 presents the three studies and their corresponding methods, populations, article titles and results sections.

Study and article	**Method**	**Population**	**Title of article**	**Reported in Result section**
I	Grounded theory	Children (n=6) age 11-16 in PHC clinic 1	*Making life work for both themselves and their parents alone* – how children view themselves in relation to their chronically ill parents in primary health care	5.1
II	Systematic literature review	Children and parents in interventions	*Informing children of their parent's illness*: A systematic review of interventions with child outcomes in all health care settings globally from inception to 2019	5.2
III	Grounded Theory	Children (n=17) age 7-17 and parents (n=32) in PHC clinic 1,2 ,3	*Sustaining family equilibrium*: a grounded theory of parental behaviour when chronically ill	5.3

Table 1: Overview of studies/articles, methods, populations, article titles and report sections in this thesis.

4.2 STUDY SETTING

This study was conducted in primary health care at three different clinics in different neighbourhoods of Stockholm, Sweden. Clinic 1 was located in a suburb south of Stockholm city centre with a slightly lower-than-average Stockholm socioeconomic status (Care Need Index CNI 1.3) (51). Clinic 2 was in a northern suburb with one of the lowest socio-economic status in Stockholm (CNI 1.9). Clinic 3 was located just south of the city centre and had a slightly above-average socioeconomic status (CNI 0.7).

The families included in this study were diverse, with education ranging from less than basic school to university degree. Country of birth mirrored that of the whole Swedish population, though the percentage of first-generation immigrants was somewhat higher in the study population then the country at large. Of the 32 interviewed parents 29 were mothers and 3 were fathers.

4.3 METHOD CHOICES

For studying a new field, an explorative method was needed. At the outset the relevant study outcomes were uncertain. Appendix 3 describes a study design which, for practical reasons of recruitment, was not possible to complete. However, lessons were learned from the attempt. Participants of the abandoned study shared the view that, as the matter is complex and personal, they did not feel their experience and their knowledge were captured by surveys: they preferred to tell their story in their own way. It was therefore decided to use interview data. Grounded theory is a suitable research method for new fields and can prepare the ground for later quantitative studies (52). Grounded theory has evolved and diversified into different varieties. In paper I constructivist grounded theory was chosen and in paper III classic grounded theory.

Recognizing the importance for adults to strive to understand children and to give them a voice, it was decided to begin with child interviews.

4.3.1 Rationale for using the Charmaz method (Paper 1)

As interview data can be regarded as constructivist data, it was clear from the outset that the Charmaz method of analysis (53) should be used. The first author chose this method since she accepted that all human knowledge is constructed between the parties involved. Interviewees express themselves in their personal way and within their own personal framework of understanding reality. The interviewer and analyst also interprets the data from within their own personal preference of expression, set in their own personal framework of understanding reality. Interview data in language form constitutes a limited but valuable construction between people. It was therefore logical to employ the research process described in Charmaz' Constructing GT.

4.3.2 Rationale for the systematic literature review (Paper 2)

The initial literature review revealed knowledge on the theme children as next of kin. But this knowledge was not collected or systematised; nor was it synthesized into a complete understanding of what interventions exist and what effects they have. To rectify this situation, it was decided to conduct a systematic review. The reason for choosing to do systematic literature review, instead of any other type of review (54) was to make sure that all relevant papers in this new field would be considered for inclusion. To achieve this, it was necessary to follow the strict rules of a systematic literature review, even though it meant searching several databases and manually sorting 8830 references to differentiate between the very many interventions benefiting parents when children are ill and the very few interventions benefitting children when parents are ill.

4.3.3 Rationale for using the classic grounded theory method (Paper 3)

Paper I produced useful insights into the children's perspective. The research continued to be guided by Charmaz for Paper III, in which the parent's perspective was analysed and evolved into a conceptual model. Journal reviewers found the paper novel and interesting but that the analysis was incomplete; they wished the level of analysis to be raised. This spurred the decision to explore the classical grounded theory method, which when applied would raise the level of analysis from the conceptual description of Paper I to a theory (Paper III).

Grounded theory was discovered by Barney Glaser and Anselm Strauss of the University of California, San Francisco in the mid-1960s as they researched dying people in hospital (55). After publication they developed the grounded theory method in their book "The Discovery of Grounded Theory" (52). Glaser resists any attempt to label the theory according to any theory of science as grounded theories are hypotheses of interrelationships between sets of categories. They do not deal with the philosophical conception of "truth"(56). According to Glaser and Holton, classic grounded theory (CGT) accommodates a range of epistemological and ontological perspectives without having to espouse any one perspective (57). Central to CGT is conceptualization: for CGT the aim is to generate a theory, which explains the main concern of participants, conceptualizes their patterns of behaviour as they seek to resolve or process that concern and conceptualizes what varies those behaviours. Through conceptualization (as opposed to description) the theory transcends person, place, and time. CGT can use any type data, including constructivist data. Additionally, CGT has clear analytic processes designed to raise the conceptual level of a theory, especially through the application of theoretical coding techniques. CGT was therefore adopted as the method for this paper.

4.3.4 Method

4.3.4.1 Paper I

Data collection: As serious illness in PHC is not usually characterized by diagnosis but rather by comorbidity and lack of function in everyday life, sick leave rather than diagnosis was chosen as the inclusion criterion. Patients on sick leave, defined as certified medical inability to work for more than 90 consecutive days (thereby excluding parents with minor and quickly-healing illness less likely to influence the children) were invited to the study. In 2015 semi-structured interviews were conducted individually in a doctor's surgery at clinic 1 with fourteen parents and six children.

Data analysis: Open coding from *the children's perspective* was conducted with constant comparison of *incidents*: children sharing examples of feelings and behaviour in relationship to their own parent were compared, one incident with another. Memos were written continuously. Concepts evolved and were compared one to the other. The memos were sorted, and a conceptual model was constructed.

4.3.4.2 Paper II

Data collection: The review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (58). The review protocol was registered on PROSPERO (International Prospective Register of Systematic Reviews) and can be accessed at https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42018085650

Five medical and social databases (Medline/PubMed (Ovid), Web of Science Core Collection, PsycInfo (Ovid), Cinahl and SveMed+) were searched in the following way. Through key articles (59-61) relevant search terms were sought. With the help of librarians at the Karolinska Institutet University Library, searches without restrictions on language, year, or publication type to identify relevant references were conducted in January 2018 and updated in November 2019. All titles were screened by CO until 2018, and by SE and AN between 2018 and November 2019. CO and one of the co-authors (SE, AN, TE or JM) read possible abstracts. The suggested inclusions were then compared. A total of 144 potentially relevant articles were selected for further review and the full text of these was independently screened by at least two co-authors. Any uncertainty was discussed in relation to the inclusion and exclusion criteria and a joint decision was made by all authors. A total of 57 relevant articles met the inclusion criteria but not all were methodologically sound: 28 had a descriptive design with pre- and post-measurements without randomization. These articles described valuable learning from mental health (including substance abuse) n=17 (60, 62-77), cancer n=6 (78-83), HIV n=1 (84), multiple sclerosis n=1 (85), acquired brain injury n=1 (86), traumatic grief n=1 (87), and critical care n=1(88). Still, as they lacked methodological rigour they were excluded. Included were 32 studies. The complete PRISMA flow diagram of identification, screening, eligibility, and inclusion of articles is shown on p. 8 of Paper II.

Data analysis: A quality assessment of the 32 included articles was then conducted using the Critical Appraisal Skills Programme (CASP) (89). A total score was calculated for each study based on relevant checklist items and each study was graded as low, moderate, or high quality by CO and either SE, TE, JM, or AN. Disagreements were resolved by discussion.

As there was great heterogeneity of study designs, contexts, populations, and outcome measures, a meta-analytical approach was considered inappropriate. Instead a narrative synthesis drawing on the framework and techniques described in ‘ERSC Guidance on Conducting Narrative Synthesis’(90) was conducted.

As a first step a model of change (91) was created. This model presents how the interventions work in a general and broad sense, why they work, and for whom (Figure 1).

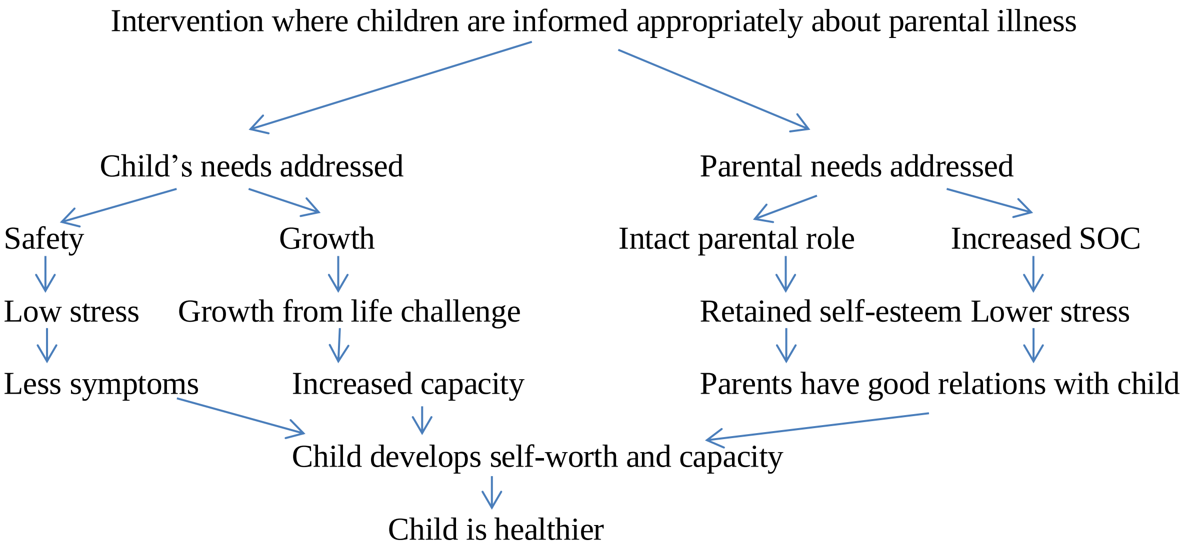


Figure 1: Programme theory model describing assumed mechanism by which interventions facilitate child's health

In a second step, a preliminary synthesis was developed. The findings were organized to describe patterns across the studies in terms of direction and size of effects.

Tabulated quantitative data were reorganized in groups according to type of parental illness. The intervention outcome, namely children's internalized and externalized symptoms and pro-social function, was tabulated as presented in the original articles. Later reports on diverse statistically significant improvement of the child's symptoms were summarized as "improved".

Tabulated qualitative data were also reorganized in groups according to type of parental illness. Intervention outcomes for the children and parents, respectively, were tabulated in the wording of the original papers, extracted, and imported into NVivo. Then a content analysis (92) of these results was manually conducted.

In a third step relationships in and between studies were explored. The results from qualitative studies in cancer and mental health settings were first analysed separately and then compared to each other.

The main insight from this systematic review was that children and parents have a shared and universal need to understand the illness and for open communication, in order to cope with and to handle feelings, irrespective of the clinical setting. This is what they receive and benefit from when they take part in well-conducted interventions. At the same time, however, it became evident that most ill parents and their children are not offered such interventions, and why this is so, was unclear.

4.3.4.3 Paper 3

Data collection and data analysis: Using Charmaz' guidance, open coding of interview data of wave 1 was conducted from *the parents' perspective*. Constant comparison of *incidents* took place during open coding: parents sharing examples of feelings and behaviours in all life areas were compared one incident to another.

In a second wave of interviews in 2018-2019 another 9 parents and five of their children were interviewed at the same clinic. *Selective coding* of wave 2 interviews took place as the coding now focused on parents' feelings and behaviours in relationship to their own child, instead of for instance parents' feelings towards other important areas in life such as work, extended family or health care. Incidents and codes were constantly compared, one to the other and rich codes emerged.

At this point the main concern and core categories were becoming clear but to achieve theoretical completeness, it was found that *theoretical sampling* was required and that more data exploring the core concepts and time processes was necessary. A third wave of interviews with ten parents and 10 children was conducted in 2019, now at two other clinics in the Stockholm region, clinics 2 and 3.

Constant comparison of incidents and codes continued. Memos were written throughout the whole process of analysis and by now were written as codes such as "children are ahead of the parents" ..." parents have lost the parental role" … "tension between parent and child". It became clear that parents and children agreed that parents should 'soon' inform their children. Soon meant immediately for the children and as soon as possible for the parents. Parents understood 'soon' as soon as the medical investigation was complete, and they had been properly informed about the illness. It also became evident that parents often do not share information about their illness with their children, even when children directly ask for it.

A conceptual model was developed and submitted as a paper to a journal. Spurred by reviewers, further analysis was needed to raise the conceptual level from that of conceptual description (constructivist grounded theory in paper 1 and content analysis in paper 2) to theory (Paper 3).

Concepts were further developed using constant comparison. Through systematic questioning it was possible to differentiate the main concern from the process by which it is resolved or processed. Memo-writing on what parents and children considered to be the ideal and un-ideal processes of sharing information about the parental illness triggered the opening up of the analysis.

Accepting that the child's comprehension of parental illness is often ahead of their parent's belief, the analysis then focused on how different parents respond to the child's comprehension. This revealed different parental behaviours in response to the child's behaviours, which in turn were based on the child's comprehension.

When sorting memos to reveal the *theoretical code* which best models the concepts developed, it became apparent that parent and child together create a context in which they both attempt to sustain family equilibrium. Thus, an important theoretical code was found to be context. It emerged that child and parent comprehension of parental illness was what varied the context most. The theoretical code *context* organizes the core category *awareness*, hence *awareness context.* From there the different awareness contexts could be conceptualized by constantly comparing one awareness context to the another by memoing in the format of a table. There was an emergent fit with Glaser's awareness contexts. Two additional contexts relevant to this study (concealed and conflicted) were developed.

Concepts and analytical understanding brought forward from papers 1 and 2 were appropriately incorporated into the analysis in paper 3. The main insight from paper 2 was that children and parents have a shared and universal need to understand the illness, to open up communication, to cope and to handle feelings, which is satisfied in interventions irrespective of the clinical setting. This insight was synthesised with the analysis of paper 1 (that children are very influenced by their parent's illness and they feel alone) and incorporated into the analysis of paper 3. This is an illustration of the position of classic grounded theory (CGT) that "all is data" (93).

Synthesising all three papers it emerged that the child is searching for meaning about what is happening within the family. Some parental behaviours undermine the child's growing awareness. This is done by the parent through normalising the impact of his or her masking and resisting behaviour on the child's identity (see section 5.3).

Memos were written continuously through the research process and form the basis of the analysis. The purpose of writing memos is to capture concepts and relationships and to gradually raise the level of analysis to a more theoretical conceptual level. A typical memo early in this study was written in Swedish, exploring concepts and ideas found directly in the Swedish language interviews. As the level of analysis was raised the memos gradually included more English and conceptual memos in the end, and the theory itself is written in English. The theory was then rendered into Swedish to make it accessible to Swedish health care.

4.3.4.4 Researcher reflexivity

It is acknowledged that both study 1 and 3 (and study 2) are of necessity affected by their author's characteristics and preferences. She found that all of her previous life experience was helpful to increase theoretical sensitivity when understanding the data and conceptualizing the theory. This experience come from the author's own childhood including illness in the family, medical training, experience of being a doctor of family medicine, and being a mother and a patient. The impact of the author on the data was not further explored in this study.

4.3.5 Ethical considerations

This study was approved by the Stockholm Regional Ethical Review Board (2013/62–31/5, 2014/1454–32/5 and PUL KI 2–3750/2014).

The dominant global framework for ethical research involving children is the UNICEF-sponsored project Ethical Research Involving Children (ERIC) (94). Studying parents and their children is ethically challenging: there are no easy answers or ready solutions for how to involve children in research in an ethical way. The ERIC framework is designed to support researcher's reflexivity, the capacity to be conscious of, and give an account of, one's actions. The following section is structured according to the four key areas to consider when planning, implementing, and disseminating research.

Harm and benefits: To decrease the risk of harmful experience for the participating children (and parents) several strategies were used. Participants were invited via their usual contacts at the clinic. It was made clear that research was being conducted, that their input was appreciated but that they were very free not to participate, without explanation. The children were invited via their parents. Parents and children came together to the clinic, were orally informed together, and had the opportunity to ask questions before signing consent forms. Interviews were conducted with parents and children independently.

Informed consent: All parents and children were informed of the voluntary character of their participation and that they were at any time were free to stop their participation. They were informed both in conversation and in writing and signed forms of consent after a possibility to ask questions. The parents invited their children and all the parents consented to their children's participation.

Privacy and confidentiality: The information shared in interviews was audio-recorded, anonymized, transcribed, and the data was kept secure. The results are reported on an aggregated level. The parents and children were interviewed individually to reduce the influence of the presence of the other one. As one was interviewed the other waited in an adjacent room with fruit, paper and pens, to pass the time. After the interviews they were individually invited to ask questions. Some had questions on the research, and these were answered. A few needed some time to emotionally collect themselves after the interview and the interviewer then waited so the person could calm down. A few times, care needs became apparent and contact with their doctor was arranged. While the benefits of this study included foremost the generation of much-needed knowledge in a new field, there appears also to have been some immediate benefits for the research participants. After the interview, interviewees were asked how they experienced it. All responded that they appreciated the interview, saying that it had given them an opportunity, often for the first time, to reflect together with someone else on a question that was important to them in their lives. Being interviewed in an open manner can itself be a positive experience. Afterwards, the interviewed parents and children sat down together with the interviewer, were again together asked about their experience, and had a chance to reconnect with each other in a calm and friendly setting before leaving the clinic.

Payment and compensation: The principles of justice, benefit and respect underpin the need for research participants to be properly acknowledged, adequately recompensed, and given fair returns for their involvement. At the same time payment should be avoided as it can distort the involvement and put children at risk of economic and social pressure. In this study children were acknowledged by the respect granted them by the interviewer, the gratitude of the author in this publication, the availability of healthy snacks during the interviews and tickets for one film show for all the child's family members.

There is a special ethical challenge if underaged children and parents have differing opinions on important matters such as a child's participation in research or treatment. In the present project the children were invited by their parents, who consented to their own involvement as well as the child's. It is unlikely, but not impossible, that undue pressure could have been put on some child to participate by their parent. The fact that fewer children than parents participated indicates that the foreseeable took place more often: a parent wished to participate but had a child who declined participation.

In sum, these strategies seemed culturally appropriate in the setting, reduced the ethical risks, and increased the chance for the child's voice to be heard and for a pleasant experience for all participants.

5 RESULTS

5.1 THE CHILD IN RELATION TO A CHRONICALLY ILL PARENT

The main concern of children of chronically ill parents' is sustaining family equilibrium, which they attempt through a process of upholding family relationships. When initially analysing and conceptualizing the perspective of the child, the children's main concern of was worded as "struggling alone to make life work for both of us". In study 3 this was reconceptualised as a shared concern with the parents of sustaining family equilibrium. Study 3 also resulted in a solid and clear understanding of the child's wish that the parent soon reveals to the child.

The struggle to sustain family equilibrium alone is processed with two main strategies, “understanding” and “adopting the parental role”, each with three six sub-categories (Fig. 2).

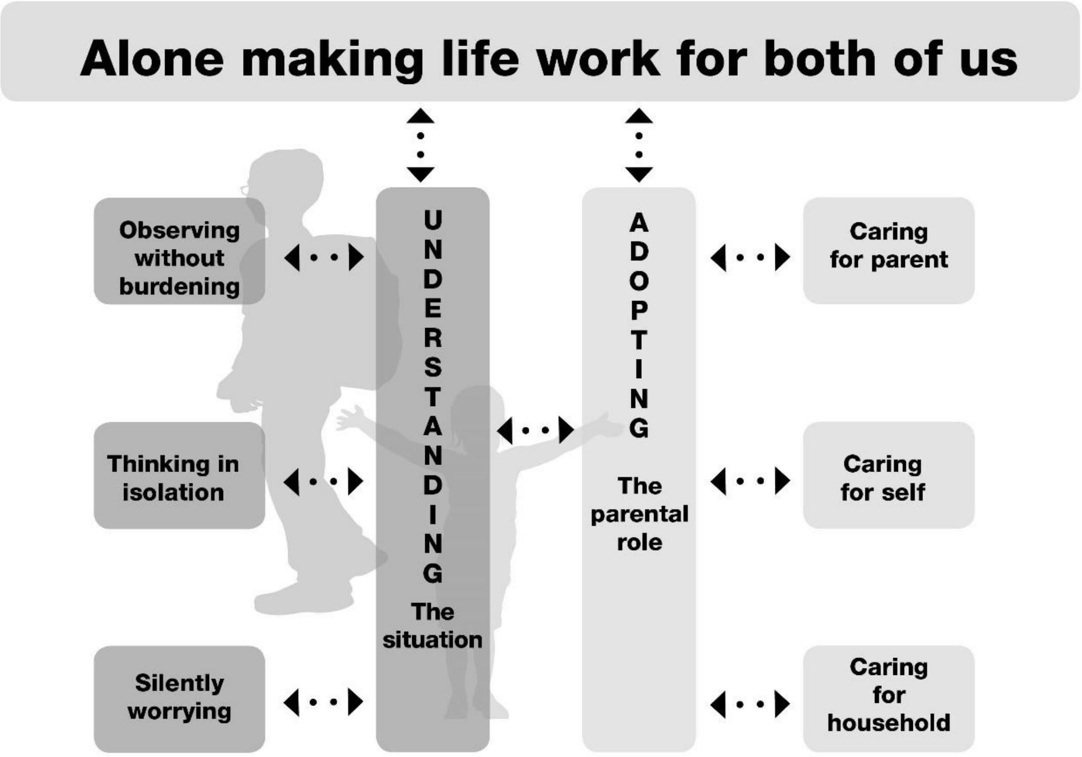


Figure 2. Conceptual model of children’s self-understanding and strategies when their parent is chronically ill in a primary health care setting.

5.1.1 Understanding the situation

A child’s understanding of reality, including the parent’s situation, grows gradually over several years. The child compares observations of his/her parent over time with their observations of other adults and thinks deeply about how things are connected. The child also observes his/her own emotions and actions and what the outcome of the actions are. In a gradual process, children struggle to understand the complex situation and relationships as shown by this dialogue (all interviewees’ responses are shown in italics):

> *I just want to know the name of the illness.*
> Have you asked your mother?
> *No…she might get sad… that’s how it is.* (B1).

5.1.1.1 Observing without burdening

To understand, the child observes the mother’s symptoms such as hip or back pain, paleness, sensitivity to light, noise, and smell; and changes in behaviour such as spending time in bed, not smiling or singing as before, not doing housework or socializing.

The child gathers that the parent wishes for things from her or him: practical help, sometimes company and sometimes not, and success at school but without homework support. The child is also aware that the family's money is scarcer than before the parent was sick. Thus, the child's observations, gained without burdening the parent with many uncomfortable questions, became an important source of information for understanding the parent's illness.

> *So, you know that your mother is keeping a great deal from you, ermm .., I can see that in her.* (B3).

5.1.1.2 Thinking in isolation

To understand the child is in a continuous process of thinking about what has caused the situation and what the solution can be. The parent often does not answer questions sufficiently and the child must accept this and think alone. Insights therefore generally grow slowly and painstakingly.

> *Why does she never open up to us? There are explosive questions in my head (B3). In the end I gave in…well, if she does not want to talk, I cannot force it out of her.*
> So, you have asked her but do not get any answers.
> *Yes* (Silence) (B3)
>
> How is it when your mother is very ill?
> *Then you're sad. I'm in my room thinking* (B1).

5.1.1.3 Silently Worrying

To understand, the child is in a constant emotional process. He or she worries about what will happen today and in the future. The child takes responsibility for preventing bad things from happening and for resolving situations that do occur. The child longs continually for nearness and normality, sometimes in active grief over the loss of positive interaction with the parent.

> *The day is really spoilt …I get worried…well, today she seems to feel bad so maybe we'll have to call the ambulance or the health advice line or something* (B5).
>
> *The first thing you want when you get home from school is to see your mother smile… when she doesn't, you see that she's not well… you get sad …you blame yourself that you can't do anything about it … why can't I help her? (B3).*

5.1.2 Adopting the parental role

To make life work for both themself and their parents the child partly takes over aspects of the parental role. The child takes it for granted that children have the duty to do this, phrasing it as "helping". Helping consists mainly of nursing tasks, taking overly care of themself and thereby relieving the parent of parenting tasks, and taking responsibility for the household. The child also performs parental tasks for their sibling(s), such as accompanying a sibling to a parent-teacher conference or doctor. One of the older children interviewed stated, "*The most important thing is that Mum maintains her leadership*", thereby showing an understanding of the burden of responsibility that otherwise falls on the child.

5.1.2.1 Caring for the Parent

To help, the child keeps an eye on the mobile phone in expectation of contact from the parent, ready to run home to assist if needed. The child guides the parent to rest, protects from light, sound, smell, fetches medicine, asks a neighbour for help, calls for medical advice or the ambulance, calms the parent and siblings, and keeps the parent company.

> *Mum rings me and needs help to carry food home from the shop… I would quite seriously like to be able to get the tube to go faster to be able to go and help her. Many times, I've run home from school because I don't want her to carry anything because of her back (B3).*

5.1.2.2 Caring for Self

The child learns from experience not to expect parenting and tries alone to do things that normally would be done together with a parent or with a parent's help, such as travelling alone, going alone to meetings at school, healthcare appointments, dentist, and taking care of schoolwork alone. Also, the child must do without social activities together with the parent, such as visiting family and friends, or shopping, swimming or to the cinema. The child must for instance, do sports without a parent's presence and independently learn skills such as baking, without a parent's help.

> *It feels like we're gliding apart…it feels like we're missing out…there are certain things parents do with their children and…we miss out on that… and it gets sad... (B3).*
>
> *I can't make her healthy, but I can take care of my studies better…. so she sees that I'm involved in things and that I can help her psychologically at least, not physically… (B6).*

5.1.2.3 Caring for the Household

To help, the children tidy, shop, carry groceries, cook, wash dishes, clean, wash clothes or walk the dog, knowing that this will relieve the parent of stress and, therefore, help the parent keep their composure.

> *I usually wipe the counter and wash the dishes and put things away… she doesn't like when it is messy…she gets stressed and panicky and easily gets angry … so I help, so she won't get stressed, as that takes her energy and makes her more exhausted" (B5).*

5.1.3 The child wishes the parent to reveal the illness, the parent's lived experience and expectations on the child

The child wishes the parent to inform them what is going on. Thereby both can remain in their respective roles and the child can experience parental initiative and nearness. The child's comprehensive needs regarding the illness centre about three themes:

5.1.3.1 The illness: diagnosis, treatment, and prognosis

The child simply wishes to know the name of the illness and what symptoms and decreased functions it causes. He or she will be relieved to know that other adults are cooperating with the parent to improve the parent's health, that the illness is not expected to get much worse and is not life-threatening. The child will also be glad to have an idea of how long it will take for the parent's health to improve.

5.1.3.2 The lived experience of the parent's inner world

The child identifies with the parent and therefore wishes to share the parent's life and feelings even when they are challenging. What does it feel like inside the parent? How does the tiredness or pain or anxiety actually *feel*? How does the parent understand how the illness began and developed? What life events does the parent connect to the illness? What dreams does the illness currently hinder the parent from realising?

5.1.3.3 The ill parent's wishes regarding the parent-child relationship

All parent-child relationships change continuously as the child grows up. Added to these changes there are now changes caused by the parental illness. The child wishes the parent to remain a parent even when ill and wonders about the parent's situation. The parent-child relationship is stabilized by the parent explaining what she or he wishes for and from the child in this time of parental illness. It helps the child to be told that the parent wishes them to be healthy and develop. Professionals and the parent are jointly responsible to help the parent get well. What the child can appropriately do to help is well-defined, age-appropriate practical chores. The parent can share his or her wish to remain a parent, to be there for the child as much as possible, even at this time. When the parent is unable to be or do something in relation to the child, it is helpful if the parent can mandate someone else to step in.

In many cases both parent and child need help to sustain family equilibrium.

5.2 INTERVENTIONS HAVE COMMON FEATURES AND EFFECTS

A systematic review of 32 studies published from 1994 to November 2019 showed that interventions designed to support chronically ill parents and/or their children have common features and effects. These new findings are presented below and summarized in Table 2.

5.2.1 Outcomes

5.2.1.1 Child and parent outcomes

Parents and children value gaining more knowledge about the parental illness, improved communication, and coping strategies; and increases in their capacity to handle negative feelings. Parent also appreciate changes they observe in their own children's behaviour, increased understanding of their own child, and they enjoy seeing their child at ease.

5.2.1.2 Child outcomes

Increased Knowledge and Understanding: By getting information about the parent's illness, the child's misconceptions were dispelled, and a more accurate interpretation of observations was possible for the child. The child understood the impact of the illness on the family relations and became aware of their own role in the family.

More Open Communication: Changes in communication made it possible to speak out. This was a gradual and interactive process. The children had needs to be able to speak in different settings about what had previously been hidden: in private with a professional, with peers, with the parents and the rest of the family, as well as one's extended network. To be able to speak within the family was essential, and this was made easier through communication in the other forums.

Children's Sense of Relief: Before the intervention the children had experienced that there was no safe place to speak out. They had been guarded and watchful and had worried about parental symptoms they observed. They even felt responsible for the situation and blamed themselves. They feared developing the same illness as their parents. After the interventions they felt more secure and felt their experience had been normalized by the unexpected comfort of connection when meeting peers in similar circumstances.

Better Access to Heathy Coping Strategies: The interventions promoted improved agency (retaining independent active steps towards plans and goals), a better ability to stand up for their own desires and the use of strategies to lead a normal life. The children appreciated being allowed to shoulder defined, small, practical tasks for the family. They needed escapism with opportunities for fun, balancing the needs of their own lives and the needs of the ill parent. They learnt that they could ask for and receive help and learnt whom they could approach.

5.2.1.3 Parent Outcomes

Increased Knowledge about Their Illness: Interventions conveyed knowledge about the parental illness and increased the parents' understanding of the illness.

Changes in Communication: The parents found that the interventions connected them with professionals who helped them find words and phrases which were helpful when talking about the illness with their children. They also practiced the skill of communication during the intervention.

Feelings of Shame and Guilt: Parents expressed feelings of shame and guilt as well as an ongoing uncertainty and fear about the future development of the illness. They also expressed a lack of confidence in how to talk to their children about their illness. Sharing their situation, feelings and experience with others reduced feelings of shame and guilt. When the parents had talked about their illness with their children, they felt relief. Participating in interventions provided opportunities for parents to observe their children's sense of relief.

Stronger as a Parent: When the illness disrupted family security, parents felt that the impact of the illness needed to be addressed. They were concerned about the impact of the illness on family roles and wished relationships to endure. They wished to remain in the role of a parent providing a safe, healthy, supportive, united, and hopeful family. Both the ill parent and the other family members needed to adjust to the needs of the ill parent. Strategies were used to lead as normal a life as possible. The parent was a gatekeeper to how, when and in what context the child was to learn about the parental illness.

Changes in Children's Behaviour: The parents observed changes in their children's behaviour, and concern about these changes made them seek assistance with the highest urgency. They felt the need for professional input. They wished their children to understand the illness better in order to reduce the children's symptoms.

Parents' Understanding of Their Children: Parents described how it was hard but necessary to hear what the children had to say and difficult to view themselves from the children's perspective, yet this communication increased their understanding of their children. The interventions opened the parents' eyes as to how the illness had affected the children, especially in the case of substance abuse.

Respite: The parents expressed relief in seeing their children have fun and enjoy activities and relationships during the intervention.

Table 2 summarize the findings.

Shared concepts	**Children outcome**	**Parental outcome**
Knowledge	Increased knowledge and understanding	Increased knowledge about their illness
Communication	More open communication	Changes in communication
Coping strategies	Better access to healthy coping strategies	Stronger as parent
Feelings	Children's sense of relief	Reduced feelings of shame and guilt
Parent specific concepts		
		Changes in their children's behaviour
		Parent's understanding of their own children increased
		Respite

Table 2. Result of Content Analysis of Outcomes in Qualitative Studies in Parents and Children

5.3 THE PARENTS SELF-UNDERSTANDING AND STRATEGIES IN RELATION TO THEIR CHILD

The main concern of chronically ill parents, as well as their children, is sustaining family equilibrium, which they attempt through a process of upholding family relationships.

> *I struggle every day … I fool myself, fool my family, fool all, trying to stand there and show that I can do it.* Parent 9.

The illness disrupts the parent’s life, absorbing much of their time and energy. As the symptoms of illness and the decreasing capacity of the parent affect family life, the parent may not be able to handle these changes. Instead, she or he focuses on upholding previous behaviours in an attempt to normalize the situation and sustain family equilibrium.

In the face of upholding behaviours and unrecognised needs, the child’s need for active parenting motivates the child to act. He or she mirrors the illness to the parent, to engage the parent in meaningful discussion. Taken up with their own concerns, however, some parents are slow to recognize that their upholding behaviour is inappropriate in a changing situation. Consequent interactions between parent and child can cause relational tensions, which bring the family into disequilibrium and potential chaos. The interactions of parent and child creates one of six awareness contexts: closed, concealed, suspicious, conflicted, mutual pretence or open (Table 3).

Understanding the family’s current awareness context provides a conceptual tool, which can be used to support parents locked in non-optimal contexts and enable them to parent their child in the way that the child yearns for.

Awareness Context	**Closed**	**Concealed**	**Suspicious**	**Conflicted**	**Mutual pretence**	**Open**
Child's comprehension of parental illness	Low	Low	High	High	High	High
Parent's comprehension of illness	Low	High	Low	High	High	High
Parent's comprehension of child needs	Low	Low	Low	High	High	High
Parent's behaviour: ***Upholding family relationships***	Upholding: Not noticing illness Not noticing child need	Masking: Accepting illness Denying child need	Upholding: Unconvinced of illness Denying child need	Resisting: Accepting illness Accepting child need	Colluding: Pretending illness Pretending child need	Revealing: Understanding illness Understanding child need
Child's Behaviour: ***Upholding family relationships by mirroring***	Noticing illness	Noticing illness	Challenging	Challenging	Colluding	Contributing
Relational tension	Low	Low	High	Very high	Medium	Low
Family equilibrium	Equilibrium	Equilibrium	Disequilibrium (slight)	Disequilibrium (severe)	Equilibrium (locked up)	Equilibrium (dynamic)

Table 3: Parental illness-induced relational change: awareness contexts of parent and child

Awareness contexts

Table 3 shows that the awareness context is a function of both the parent's and the child's levels of comprehension regarding the parent's illness, the parent's level of comprehension of the child's need for facilitative parenting, and the respective upholding and mirroring behaviours of both.

5.3.1.1 Closed and concealed awareness contexts

In both the closed and concealed awareness contexts, the child begins to notice changes in the parent: noticing symptoms and loss of function. The child also notices that family life and social life are in some way compromised, perhaps that the home is less well cared for. The child, however, is unaware that these effects are caused by illness.

In a closed awareness context, the parent is also unaware of the illness and is upholding previous behaviour as if the illness or the child’s needs have no effect. In a concealed awareness context, the parent has a level of comprehension regarding his/her illness and seeks to mask or conceal its effects, verbally rejecting the child’s noticing, probing and proving statements, insisting that things are fine or not-so-bad. The relational tension is low, and the family relations are in threatened equilibrium.

5.3.1.2 Suspicious and conflicted awareness contexts

In both the suspicious and the conflicted awareness contexts, the child begins to understand that the parent is ill. In a suspicious awareness context, however, the parent remains unconvinced both of his/her illness and of the child’s needs in relation to the illness. The parent continues to uphold behaviours and deny the child’s needs. In response, the suspicious child challenges the parent by probing for more information: verbally stating parental symptoms and asking questions in the hope that the parent will reveal the nature of the illness and the shape of things to come. Since the parent does not reveal, the child also seeks to prove the parent’s diminishing capacity and family disequilibrium: meaning that the child tries to contribute to the awareness process by pointing out facts and explaining and contextualizing the parent’s symptoms to the parent.

In a conflicted awareness context, the parent understands both the nature of his/her illness and the child’s needs but, uncertain of their own competence to engage with the child, resists the child’s challenges: actively denying or diminishing the child’s changing awareness and their own symptoms and loss of function. The relational tension is high or very high and family relations are in slight or severe disequilibrium.

> *My daughter says: Mum, why are you sad again? I say: No dear, no, I am not sad.*
> Parent 12

5.3.1.3 Mutual pretence contexts

In a context of mutual pretence, both child and parent are aware of the illness and the child´s needs. The parent invites the child to collude by pretending either that they do not know, or that what they both know does not matter. The child accepts the invitation and colludes to avoid further erosion of parental role; or declines to collude and they remain in the conflicted awareness context. If the child colludes, the relational tension decreases somewhat, and the family is in a locked-up equilibrium.

5.3.1.4 Open awareness context

In a context of open awareness, both parent and child understand the nature of the illness and the child’s needs. The parent engages in discussion with the child to reveal and acknowledge the illness. Under these circumstances, the child can cease any previous challenging or colluding behaviours and contribute to family relationships such that relational tension is low, and the family is in dynamic equilibrium.

5.3.2 How the parent-child awareness moves from one context to another

All families will experience the closed awareness context and at least one other: what other contexts are experienced varies.

The way in which awareness contexts evolve from one to another depends mainly on: (i) the parent’s characteristics (ii) the pace of development of the parent’s comprehension of the parent’s illness by the parent (iii) by the child and (iv) on the pace of the parent’s changing understanding of the child’s need for parenting. Two types of parent emerge: ‘Facilitators’ and ‘Resisters’.

5.3.2.1 Types of parent: Facilitators and Resisters

Once the illness is noticed, both parent and child wish the parent to oversee the process of increasing awareness with the child. In particular, yearning for the stability that active parenting brings. Parents who manage this process are Facilitators.

Facilitators are characterized by having higher degrees of self-worth; self-knowledge; comprehension about their illness; parenting skills and emotional stability. They have a higher need, and hence motivation, to facilitate their child’s comprehension. The greater the degree to which they possess these characteristics the better they are likely to be at facilitating the awareness of their child. Importantly, having the words to explain, the patience to endure and the emotional capacity to support the child’s need for the parent to remain a parent, are traits that differentiate the Facilitator from the Resister.

The Resister is characterized by having lower degrees of self-worth, self-knowledge, comprehension about their illness, parenting skills and emotional stability. These parents also need to support their child but recognise that they lack the capacity and ability to do so in the way the child needs: their pain is compounded.

> *“To wish to be there for once child, but not be able to, is the most difficult of all”*
> Parent 4.

5.3.2.2 Ideal process though awareness contexts: Driven and facilitated by parental awareness

An unproblematic pattern of evolution of awareness is that of moving from closed to open awareness. Here the relational tension remains low and family equilibrium is sustained. This ideal process happens clinically, but is rarely noted by the clinician, as there is no prolonged problem situation to observe. The facilitating parent comprehends and accepts the illness and the child’s needs. The child has an age-appropriate need for awareness development and therefore has a natural drive to understand themself, their parent, and the relationship. The parent propels the awareness development by soon revealing to the child a reality-based understanding of both the illness and the child's needs; and they enter an open awareness context together. The parent is motivated to reveal, considering this a part of their parenting responsibility.

> So, what makes you go on?
> *"My stubbornness and my children"* Parent 14.

The parent has the capacity to welcome what the child notices and to answer their questions. The child remains relationally calm and contributes in the context of open awareness.

5.3.2.3 Variation from ideal process: driven by child awareness and the parent's resistance to the awareness process

Driven by the child's increasing comprehension, more problematic patterns of evolution of awareness emanate from closed or concealed awareness contexts to suspicious or conflicted contexts.

In these contexts, relational tension grows high and the family is in disequilibrium, sometimes severely so.

The resister does not initially comprehend or accept the illness or the child's needs. The child is noticing and is trying to move the awareness context by probing and proving. The parent doubts his/her capacity to reveal and so hinders the development of awareness by masking or resisting. The child strives for increased awareness as part of a general, age-appropriate need to know. The more the parent resists and the child challenges, the more they become locked into a conflicted-awareness context. As the parent lacks the capacity to welcome what the child notices or to answer their questions, the child becomes relationally upset and the high relational tension feeds into the awareness context. The relational tension is very high, and the family is in disequilibrium.

> *The greatest difficulty is not accepting one's situation. Denial, denial.* Parent 3.

Both child and parent are here trying to sustain the family equilibrium and uphold family relationships in a context of increasing awareness of illness and child needs, but by using different strategies. In mirroring, the child is trying to sustain the family equilibrium by noticing, proving, and probing to move the common awareness context to open.

The parent is using two different behaviours to sustain family equilibrium: masking and resisting. Parents and children can remain in a suspicious or conflicted awareness context for a prolonged time (months, years, and decades). They do, however, have the option of colluding to create a context of mutual pretence, or the parent has the option of revealing and moving them both into an open awareness context.

5.3.2.4 Context of Mutual Pretence

To reduce relational tension and increase family equilibrium the parent and child might choose to collude, to pretend that they do not know, or that what they know does not matter and to uphold a mutual pretence that all is well. The parent invites the child to collude and the child might agree so as not to lose a positive parental figure psychologically and socially. If the child declines to collude, they will remain in the conflicted awareness context. A context of mutual pretence can be maintained for a prolonged period (months, years, and decades).

5.3.3 How to escape suspicious, conflicted, or mutual pretence awareness contexts – by revealing

To create a dynamic family equilibrium the parent needs to reveal the illness and become a facilitator of the awareness process. To do so, these parents need high degrees of self-worth.

The parent observes their child and sees changes in his or her reactions. They describe how the child notices and reacts to the fact that the parent does not go to work, go shopping or go out to meet friends, is inactive at home, and that the home is messy and poorly cared for. The parent observes that their child helps them with their symptoms, does more household work and supports them emotionally by explaining and contextualizing the parent’s symptoms to the parent, especially when in much pain, anxiety, or sadness.

The parent notes how the child also needs to take care of themself more as the parent lacks capacity. The parent understands that the child lacks access to a calm and happy parent but must choose to be either alone or in the crossfire of parental irritation. The parent explains that the child speaks of the parents’ symptoms and lack of capacity and asks about the illness. Parents can describe these observations very well. They realize that their child is lonely in the gradual acceptance of the parental illness. However, they share very few reflections on the observations and offer no suggestions on how to assist their own child.

> *Now that I have become ill, she has had to take greater responsibility.* Parent 4

The parent understands that their inability to engage in conversation and instead responds by denying the facts or giving vague answers such as “I’m tired” or “It hurts”. This is insufficient for the child. The parent attributes their inability to speak mostly to their own perceived limitations. These consist of insufficient understanding of their illness, inability to be in touch with their own negative feelings, dreading that the child would pity and diminish them, difficulty in creating calm and secluded time and space with the child, failure to grasp their child’s need to understand the illness, difficulty in finding the correct words and being unsure of their capacity to answer the child’s questions. The inability to speak is to a lesser degree attributed to concern that they will worry or burden the child. Motivation for why parents wish to speak to their child about their illness is guilty consciousness for not parenting sufficiently and their own childhood experience of the harmful effects of secrecy in their own birth families.

The child wishes their parent to reveal the symptoms and diagnosis, the treatment, the prognosis, their inner feelings and their self-understood life story.

> *The sick one should tell, the one with the secret.* Child 7.

The children wish the revealing to take place in a safe, relaxed, and calm atmosphere, preferably privately in the family home; or if needed, together with professionals at home or at the clinic. The children wish their parent to reveal actively to them by telling them what is going on, inviting them to discuss and answer questions. If this is not possible for the parent, the children accept passive revealing.

5.3.4 Parents wish primary health care to support the learning processes

Chronically ill parents in PHC often need support to regain initiative in parenting.

> *"I need your support, from both doctors and psychologists. I wish you to remember that".* Parent 3.

Parents wish for support from PHC first for themselves in their illness and then in relation to sustaining family equilibrium. Parents wish their GPs to relate to them in a coaching manner. Dimensions of coaching include a continuous, trusted, and supportive relationship where they wish their illness to be diagnosed, explained, and treated in a coherent high-quality way. Then they need support in verbalizing their parenting situation, reflecting on what their child notices about the illness and the child's current comprehension and needs. After receiving this support, the parent seeks to speak with the child about the illness, either alone or together with a PHC professional.

6 DISCUSSION

In the Prologue a vignette of positive parental action was presented, where a mother introduced her child to her doctor and invited them all to a conversation about her illness. The present work has conceptualized what that mother understood and what made it possible for her to invite her child and doctor into an open awareness context to their mutual benefit: it shows us what can be achieved. Given the (relatively recent legal requirement) to involve children as next of kin, this understanding shows us what ought to be achieved and this theory explains how it can be achieved.

A synergy arises from the three papers that comprise this study: Analysis of all three data sets reveals that the chronically ill parent and child share the same main concern of sustaining family equilibrium. Analysis conceptualises what this author experienced in practice that many do not achieve an open context and family equilibrium. This theory explains that for some families the way that each party addresses their shared concern causes both parent and child to become locked into the misery of family disequilibrium and tension, where the child feels lonely and isolated and the parent feels inadequate.

The theory also shows us that there are different trajectories that the parent and child relationship can follow and enables us to understand how and why some interventions bring relief to both parent and child through bringing about a change in their shared context.

We will begin by discussing the unified main concern of parents and children and will then continue discussing the results in relation to understanding the child of impaired parents, chronically ill parents, awareness contexts, and the implications on policy and practise.

6.1 SUSTAINING FAMILY EQUILIBRIUM: A SHARED CONCERN

The main concern of chronically ill parents and their children is sustaining family equilibrium, which the parent attempts through a process of upholding family relationships and the child attempts through mirroring. Parents uphold family relationships as they long to be the one they are, in their current role and in their important relationships. Thus, they strive for both intra-personal coherence i.e., the experience of a coherent self and for inter-personal coherence i.e., the experience of coherent relationships with self *and* important others.

The child wishes to be welcomed both as an individual with a personal perspective and as a child of the parent. The parent also wishes to be welcomed as an individual with a personal perspective and at the same time to experience recognition of their current role as parent of their child.

Both parent and child long for a mutually fulfilling parent-and-child relationship. They wish to be viewed as one interconnected unit where the potential of one cannot be realized without the realization of the potential of the other. This fundamental stance was consistent in all the interviews and did not vary by diagnosis, socio-economic situation, or cultural diversity of those interviewed. It gives guidance on how to approach the design and implementation of interventions. This does not preclude the necessity and possibility, in extreme situations of parental illness, to protect the child from overpowering experiences.

6.2 STUDY EFFECT ON CHILD OF IMPAIRED PARENTS

‘Child of impaired parents’ is the bibliographical key word for a child of chronically ill parents. In PHC we do not usually use the term ‘impaired’, but if we think of it as impaired to live and function as previously, it is a useful concept.

This study has made it more visible that any child, healthy or ill, in primary health care might be a child of impaired parents. If so, the child and the parent operate in an awareness context about the parental illness. This awareness context has a negative or positive impact on the child. To improve the child’s chances of health it is appropriate to explore the home situation and awareness context. It is probable that the child sees him- or herself as struggling alone to make life work for themself and the parent(s).

Previous research has documented the effects of being a child of chronically ill parents in the settings of psychiatry, cancer, and HIV care. What is new is that it is that the present work has shown that PHC is also a setting where serious parental illness is treated and where children are affected. This is clear from the children’s main concern “sustaining family equilibrium”, which they attempt to resolve through a process of mirroring the parental illness. From the child’s perspective the family equilibrium is threatened. From the child’s perspective the family equilibrium is threatened. Taken together with our previous knowledge of the importance of family relationships (95) for the health of the child, this must be understood as serious. Children show their need for support by viewing their situation as very difficult and through their outspoken wish for their parents to reveal the illness. For this reason, interventions should be developed for use in PHC. In interventions from other settings (96) the children valued increased knowledge and understanding, more open communication, better access to healthy coping strategies and their sense of relief. It is reasonable to hypothesise that children in PHC would also value these aspects if offered interventions there.

6.3 STUDY EFFECT ON UNDERSTANDING IMPAIRED PARENTS

There is extensive literature on understanding chronically ill patients, including those in a primary health care setting. There is also much on parenting an ill child; but extremely little on an ill parent parenting a healthy child. Studies of the management of chronic illness in primary health care (97, 98) and frameworks aimed at improving quality of care for the chronically ill (99) conspicuously lack the perspective that the patient might be a parent with parenting responsibilities. The present study focuses on an adult patient being a parent with the challenge of sustaining family equilibrium while ill. The parent will be in an awareness context with their child, and sometimes the family is in disequilibrium and this drains the parent’s energy. This is important to know and regulate as the patient lacks energy overall while needing energy to recover health. After the interviews, parents were asked how they experienced the interview. Most stated that they were relieved to speak, for the first time, about their parenting situation while ill and that the interview had helped them to better understand themselves and their children. They also admitted that they had not believed they were welcome to speak at the clinic about this aspect of their lives. They found it very valuable and hoped this support would be available forthwith in PHC. Parents show their need for support by being locked in suspicious, conflicted, or mutual-pretence awareness contexts. They need support to become revealers as this can contribute to normalizing and strengthening the parent-child relationship. As the parent reveals, the child gets information about the illness and at the same time experiences how the parent takes an important parental initiative in relations to them. The parent also benefits through the act of revealing by strengthening parental identity and parental self-worth and, by extension, the motivation and capacity to pursue treatment and rehabilitation. This more specific support can be incorporated in a general support model such as the Family Model (100). This brief intervention for clinicians in adult mental health services working with parents experiencing mental health problems, is currently being introduced in Sweden.

6.4 STUDY EFFECT ON AWARENESS CONTEXTS

Awareness contexts are well-known in sociology. The concept was presented in 1965 by Barney Glaser and Anselm Strauss in their work “Awareness of Dying”(55). Awareness contexts facilitate analysis of the total combination of what each interactant in a situation knows about the identity of the other and of his own identity. The authors suggested a typology of four different types of awareness contexts: closed awareness, suspicion awareness, mutual pretence, and open awareness. In the present work awareness contexts emerged as a helpful conceptual tool to structure the theory. Awareness contexts are used in many settings, including, for example, mathematics. Here we explore the concept and compare it with the use of awareness contexts in dementia.

In 1997 Hutchinson et al studied the explanatory value of awareness context theory for social interactional issues in early probable Alzheimer's disease (101). They show how awareness contexts provide a useful way of thinking about the nuances and complexity of social interaction in early dementia, giving possibilities to suggest intervention to improve care. In 2005 Hellström et al reported on the interaction of spouses when one is affected by dementia (102). They conceptualize how couples actively work to construct awareness that mostly manages to maintain both spouses’ sense of self as well as the integrity of the relationship. They suggest that “mutual acknowledgement” of the diagnosis and a subsequent focus on maintaining a meaningful life in the present create a “nurturative relational context in which living with dementia unfolds”. These findings are relevant for studying the conceptualization of the positive state in which parents and children in an open awareness context can live. Also, in 2005 Marwit et al study couples’ communication when one member has early dementia. They find that the demented partner maintains an idealized perception of communication and marital satisfaction not matched by the other partner. Where communication by both is acknowledged as mutually open there is an accompanying elevation in scores on marital satisfaction and intimacy. This finding resonates with the concealed, conflicted, and open awareness contexts of our study. Marwit et al present a six-category typology of awareness contexts (103), adding two more between mutual pretence and open, namely benevolent and limited. The benevolent awareness context was defined as "one member, motivated by what was self-identified as love or compassion, actively restricts the range or depth of topics discussed to reduce potential or perceived "harm" to the other. In the limited awareness context, "both members of a couple are aware of a serious problem, but only Spouse A is willing to discuss it openly. Despite many efforts by Spouse A to share thoughts and feelings, Spouse B will only accept part of what is communicated and blocks further discussion whenever possible". This study also suggests six awareness contexts, adding concealed and conflicted to Glaser's and Strauss's. How the awareness contexts are defined and into how many types they are divided may depend on the area of study, the inclination of the analyst and what is useful and memorable to the user of the theory. There are similarities but also important difference between spouses where one has dementia and parents and children as next of kin. Similarities lie mainly in the fact that in both cases family members are trying to understand and live harmoniously with family equilibrium under the pressure of illness. The main difference is the vulnerable and potent state of a child. Spouses are adults, children are children; and children have special rights because of young age and special vulnerabilities. Children are much more dependent, also legally, on their ill family member, compared to spouses. Further, the ill spouse is affecting an adult with previously formed self-understanding and capacity. The ill parent is affecting a child in the process of forming his or her own self-understanding and capacity. The spouses are both in the later part of life. The child is in the first part, with a naturally increasing awareness and capacity, needing to be welcomed by the family and community.

6.5 STUDY EFFECT ON POLICY AND PRACTICE

Children-as-next-of-kin is a theme which, when explored, creates an opportunity for positive synergy with other important themes such as protection of maltreated children and young carers. The theme also contributes to understanding preventive child-health efforts, the centrality of high-quality treatment for parents, and parental support. It also highlights the need for continued training for health care professionals to be able to handle the complexities.

PHC professionals have previously been aware of laws governing maltreatment of children. The need to identify maltreated children and those exposed to intimate partner violence must be stressed: these children need protection and effective treatment (104). Children as next of kin is also a concept close to, but not equal to, the concept of young carers. Young carers are children under 18 years of age who care for a parent or other relative in a way which in scope, type and complexity is not age-appropriate (105). The situations range from having a parent suffer from and die of Huntington's disease (106) to influencing many children's attendance in schools in Sweden (24). A screening tool for young carers has been developed (107).

In policy and practice there is a need to recognize these different vulnerabilities separately from each other. At the same time, it is critical to recognize that vulnerabilities tend to cluster

(95). A specific child might fit into none, one or several of these categories. Consciously recognizing this makes it possible to address the different situations both specifically and sometimes together. Also, beginning to address one aspect, for instance that a child is a child next of kin, might open a possibility to also address the fact that a specific child is a young carer and/or maltreated and/or abused.

Children as next of kin have previously been systematically explored when, in psychiatry- and cancer care, parents are very ill, where parental illness might lead to early death or severe physical, mental, or emotional absence. The special characteristics of PHC might make it a fruitful learning ground in the study of children as next of kin. It is close to everyday life and integrative in outlook. PHC retains patients with relatively benign illnesses where the effect is relative and there is possibility for improvement. Therefore, here is realistic hope for the future of the parent-child relationship. In this situation it seems reasonable to start with the assumption that it will be possible to strive for the best for the “parent-child unit”.

The children-as-next-of-kin concept is also a potentially fruitful learning ground for professionals in family medicine concerned with interactions between parents and children. This is much needed as there have long been efforts to train professionals to recognize and report children who they suspect are being maltreated and abused but, unfortunately, the efforts have lacked sufficient effect.

There are several reasons why children-as-next-of-kin is a suitable theme for GPs to learn. It ties in closely with the professional identity of the professionals. The topic is within GPs’ core competence i.e. to help the patient understand their illness and their own child. Conversation with the parent about children as next of kin necessarily needs to be strictly on a voluntary basis and fully on the parent’s terms. This means that the professional does not need to feel that they risk their therapeutic alliance with their patient when bringing the topic up. Training professionals to take responsibility for children as next of kin will hopefully increase their capacity and willingness to take responsibility for relating to child maltreatment and abuse.

6.6 LIMITATIONS

The criteria for evaluating grounded theory are fit, workability, relevance and modifiability (56). Fit refers to how well the concepts match the patterns they represent. Workability refers to the ability of the theory to explain and interpret the behaviour with much variation and to predict future behaviour. Relevance means the significance of the theory for the participants in the substantive area. It is the intended audience of the theory who should judge its relevance, in this study primarily health care professionals in primary health care and children and parents. Modifiability refers to the possibility to modify the theory to different settings and situations. Conceptual integration has been achieved through the use of theoretical codes (e.g. context, typology, basic social process), which necessarily requires the concepts to fit the patterns. The theory recognises the main concern and accounts for how parents and children address their shared concern, which satisfies the criteria ‘workability’. In discussion with healthcare professionals and parents, the study excites and engages them demonstrating relevance. Finally, this theory can be modified to other situations when parents need to renegotiate how they sustain family equilibrium. Examples of such situations in PHC could for instance be when parents lose job and income, or family life is disrupted by death of partner or divorce.

7 CONCLUSIONS

Five different types of contribution to knowledge reported in this thesis are outlined in Table 4. The main contributions are marked in *italics* and elaborated in the chapters Discussion and Points of Perspective.

Contribution	Supported	Added	Challenged	New
Theoretical literature: Child as next of kin	Understanding of child as next of kin from psychiatry and oncology literature	*Centrality of child as next of kin in primary health care*	Absence of literature in primary health care	*Grounded theory of explanation of illness awareness between parent and child.* *A conceptual framework for understanding how ill parents manage or fail to manage the parent child awareness context.*
Professional (practical) literature: Children as next of kin	Professional literature on the topic of child as next of kin in social work	*A suggestion of what to do in primary health care*	Absence of professional literature in primary health care	*A conceptual framework by which to organise efforts for children as next of kin.* *A theory for both professionals and parents including the child's perspective.*
Practice	*Possibility to apply intention of the law* *Introduction of the concept "awareness*	*Conceptual framework from the perspective of parents and children*	*Neglect of child as next of kin in primary health care*	*A theory with which to inform the management of clinical reality.*

	contexts” as a tool for improved clinical activity.	*enabling an outline of suitable clinical actions possible to take by a single individual professional and/or clinics/ whole health care system.*		*A conceptual framework for professionals handling patients and their children.* *A conceptual framework for parents to manage awareness contexts with their children when ill.*
Research design	The appropriateness /shortcomings of qualitative research in primary health care	The integration of data from a systematic review into a grounded theory	Lack of focus on research in primary health care	*A conceptual framework capturing the complexity of the interrelationships between variables* *The basis for a quantitative survey: dependent variable= family equilibrium or awareness of parental illness*
Method	Illustrating that CGT produces empirically grounded theories explaining patterns of social behaviour in a new substantive area	To the literature of implementation of CGT by generation of a new theory in a new substantive area.		

Table 4. The Contribution of this Thesis to Knowledge

This thesis has impacted the theoretical literature on children as next of kin in primarily two ways: by making it clear that the theme child as next of kin is central, but previously overlooked, in primary health care; and by contributing a theory of the detailed interactions of parent and child, showing how they manage or fail to manage their common awareness context about the parental illness. It has also impacted the literature on chronic illness in primary health care by raising awareness about the possible impact of family disequilibrium for some patients.

For practise this thesis has implications. The study both points out the current neglect of child as next of kin in primary health care and highlights ways in which to apply the intention of the law. It provides a conceptual framework enabling an outline of suitable clinical actions possible to take by a single individual professional and/or clinic/ or whole health care system. The framework can also be used for informing management of clinical reality, for increasing professional understanding of their patients and for parents to manage their awareness contexts with their children when ill.

Professional literature can now be developed. A humble beginning of what to do in PHC is included in Section 8.2. But to change clinical reality substantial and persistent effort is needed both by clinicians and policy makers, as discussed in Section 6.5.

8 POINTS OF PERSPECTIVE

8.1 FUTURE RESEARCH TO DEVELOP INTERVENTIONS IN PRIMARY HEALTH CARE

It is now possible to start developing interventions for children as next of kin in PHC. To test interventions, relevant variables must be identified. This study provides a basis for a quantitative survey where the dependent variable could be family equilibrium or shared awareness of parental illness. Then different efforts to affect "comprehension of illness" in the parent and child can be tested. When one or two interventions are functional and effective, their effects must be tested against each other. In PHC different professionals have complementary roles. It would also be helpful to study what different professional groups in PHC see as their natural contribution when supporting parents to become revealers. From there, a suitable way for different professionals to work as a team can be clarified.

A conceptual framework capturing the complexity of the interrelationships between variables is proposed in this thesis. Future interview studies could explore how different family settings influence the framework. How is the framework influenced in the population categorised as parent of babies and pre-school children where the child's awareness is influenced by their young age? How is it influenced by the presence of siblings with a small or large age difference? How is the framework influenced by the presence or absence of a healthy parent? And by the gender of the parents and children?

In addition, it is possible to further explore the child's position as outlined in Papers I and III. The child is frustrated and alone because of a degree of awareness but not allowed to share this awareness with the parent. Not allowed to acknowledge the parent's illness, the child is also disallowed from acknowledging the harm arising from the parent's masking and resisting behaviour towards her or him. Are these normalising behaviours of parents (*I'm fine and so are you*) affecting the child's identity? What happens if a parent never accepts the illness and the child's needs? Does the child need to become mature enough to remove themself from the situation to be able to realise the effect of the illness? What facilitates such maturation?

Also, there is an opportunity to find general implications by exploring in what other situations awareness contexts are critical for understanding the behaviour of people in emotionally complex situations. Where else does something similar happen?

8.2 CLINICAL IMPLICATIONS: WHAT TO DO IN PRIMARY HEALTH CARE

8.2.1 Offer ill parents support and knowledge

8.2.1.1 Patient consultation: developing, training, and learning a coaching style of medical consultation including all major dimensions of adult patient life

Parents wish their GPs to relate to them in the manner of a coach, providing a continuous supportive relationship and a context of trust. This requires stable work conditions and career-long self-development on the part of the GP. The GP needs to be practical and to structure the doctor-patient relationship and cooperation. The relationship needs a physical aspect including physical examination, physical treatment and physical dealing with administrative needs such as referrals and sick listing. The coaching also includes a mental dimension where the GP gains coherent understanding of the whole illness situation and then helps the patient to a coherent understanding and a coherent plan for the healing of the situation, including emotionally balancing the care process (108).

To make the whole illness situation coherent, the major dimensions of the patient’s life need to be explored and comprehended. Medical students are trained to make sense of the symptoms, the investigation leading to diagnosis and treatment. This often works well but is often challenging when patients have symptoms that are not readily diagnosed and treated with current knowledge. There is a need to research common multifaceted complaints in PHC to improve knowledge and treatment standards to be relevant in PHC. In further training, GPs hopefully have developed the capacity to be patient-centred and together with the patient to explore the effect of the symptoms on work and private life. There is now an added opportunity, to use the theory of upholding family relationships in a context of increasing illness awareness, to understand whether the individual patient’s parenting situation is one contributing factor to the tensions experienced. It is a common clinical situation, noticeable to clinicians, that family tension is high when parents and children are in suspicious and conflicted awareness contexts. The theory implies suggestions for how this tension can be decreased, family equilibrium re-established and circumstances for the health of the parent and child improved.

8.2.1.2 For chronically ill parents: assess their awareness context

When a parent in PHC is diagnosed as chronically ill, it is timely to collect information by which to assess the patient’s level of comprehension of their illness. From that assessment, it is possible first to hypothesise, and then establish, the child’s level of comprehension of their parent’s illness and the parent-child awareness context. By asking the parent what the child says and does in relation to the ill parent their shared awareness context can be confirmed. Ask open questions, and thoughtfully listen to the parent’s the answers, their awareness context can be hypothesized and gradually adjusted and refined as needed.

8.2.1.3 For chronically ill parents: coach the parent about their own illness

Using a coaching-like style, the dimensions of the illness (diagnosis, treatment, and prognosis) need to be explored until a functional common understanding of the illness is reached. To begin with, the GP needs to listen to the patient to gather information on her or his understanding and to validate their experience. Then a shared understanding of what the medical results mean in the life of this patient needs to be reached. It is helpful to have the patient tell their understanding so the words he or she prefer can be used jointly and possible knowledge gaps can be addressed. Ask if the patient thinks the investigation seems correct. If yes, that parent has entered at least a concealed awareness context. If the parent does not think the investigation seems correct explore what makes them reject the diagnosis/treatment/prognosis. Loop back in the process and listen again. Several loops may sometimes be needed to create a common understanding of the illness.

8.2.1.4 For chronically ill parents: coach the parent about context management

To help the parent to sustain family equilibrium it is helpful to offer available scientific knowledge on the topic, and specifically in this setting, that children have a need for parents to manage the awareness context between them. Offer emotional and practical support in the exploration of how to do this, for instance by stepwise reflecting together with the parent on the following questions:

> What has the child, in the view of the parent, so far noticed of the parental illness?
>
> Has the parent noticed signs that the child comprehends that something is going on with the parent?
>
> Has the child done or said something to indicate that he or she understands that the parent is ill?

If so, recognise that the child now has comprehension needs about three different themes:

The diagnosis, treatment, and prognosis. The child simply wishes to know the name of the illness and what symptoms and decreased functions are connected to it. The child also wishes to understand that adults in cooperation with the parent are trying to improve the parent's health by for instance life-style changes, physiotherapy, psychotherapy and medication. The child also needs to be told, if this is so, that the illness is not expected to get much worse and is not life-threatening, but that it will take weeks or months or even years to see improvement in accordance with the prognosis.

The lived experience of the parent's inner world. Children identify with their parents and they wish to share their life and feelings. They wish to know: What does it feel like inside the parent? How does the tiredness or pain or anxiety feel? How would the parent describe how the illness began and developed? What life events does the parent connect the illness to? What does the illness hinder the parent from?

How does the parent now wish the child to relate to her or him? The child-parent relationship changes continuously, mostly because the child is growing up. Added are now also changes caused by the parental illness. The child wishes the parent to remain the parent even when ill. The parent is helped to retain the parental role by explaining that professionals and the parent are responsible to help the parent get well. What the child can appropriately do is help maintain some well-defined, age-appropriate practical chore. It is helpful to the child that the parent explicitly tells the child that the parents wish her or him to be healthy and develop during this period in their lives. The parent can disclose that they wish to remain the parent, to be there for the child as much as possible, even when ill. When the parent is unable to do something, it is helpful that he or she openly mandates someone else to step in.

When the child's needs to understand are understood, provide the parent with input to gradually move the parent's comprehension towards wishing to establish an open awareness context with their child about the illness. Normalize the situation by telling the parent that it is normal and desirable for all children to develop their awareness of themselves, important relations and situations. The parent may, after receiving this support at the clinic, and maybe with a simple note stating the above points, be able to communicate alone at home with the child. The parent might also wish for more support. Offer to meet the parent and child to listen to them, help foster their comprehension and answer questions.

8.2.2 Increase professional competence through training and reflection

Professionals in primary health care can learn what tends to happen between parents and children when parents fall ill. They can also learn how they can support the parents' learning process about sustaining family equilibrium in times of parental illness. The professionals' learning process needs structure, guidance, and time. This is worthwhile and an opportunity to implement the United Nations Convention on the Rights of the Child (3), now law in Sweden, stating that children should enjoy rights including the right to be listened to, and should be given special protection, opportunities and facilities. For this to become reality, professionals must be trained, and parents supported.

It is suggested that the topic children-as-next-of-kin should be included in professional university training for all health care staff (physicians, nurses, psychologists, and other health care professionals). The topic also needs to be part of further training when the professional has gained real clinical experience. A specific licenced training needs to be developed and offered to physicians, nurses, and psychologists.

8.2.3 Cooperate with all resources in the local community

To learn to provide children with opportune circumstances for growth and development there is a need for cooperation between all stakeholders in the child's life. Cooperation with school, social workers and non-governmental organizations is needed. For primary health care to do this it must be able to meet the other stakeholders during work time. Cooperation within the local community can be affected in many ways. One current suggestion is The Family Model (100).

9 ACKNOWLEDGEMENTS

I would like to thank the informants, parents and children who so generously contributed their experience to this research. Thank you for trusting us.

Also, I thank all those who made this learning process possible:

My main supervisor Solvig Ekblad, professor and head of the research group Cultural Medicine, Department of LIME, Karolinska Institutet research group, for her capacity in qualitative research and for her support through all the professional and private ups and downs of this process.

My co-supervisors:

Jörgen Månsson for initiating PhD studies as a possibility in the Carema company and for supporting this project to completion.

Tobias Edbom for teaching me analysis of quantitative data, computer tech support and for contextualizing our project from the perspective of child psychiatry.

Anna Nager for a solid perspective on family medicine, help with qualitative analysis and scientific writing and unfailing encouragement.

Erica Rothlind for fellow learning and support during our PhD journey.

Victoria Blomqvist for informing study participants and administration. With your compassion and systematic work, you enabled the parents and children to participate.

Masters students Maria Fahelson, Maria Singer, Moa Holmsved, Kent Sahin, Julia Lönnborg and Malena Reventlid and MDs Syamala Nalluri and Mariam Melles, for uplifting cooperation in interviewing parents and children.

The "Allmänmedicinsk Forskarskola" PhD programme at Karolinska Institutet and its participants for making research comprehensible and fun.

The "Forskarnätverket Barn som anhöriga" research network for common interest and efforts for children as next of kin, and

Helen Scott at Grounded Theory Online for the troubleshooting seminar and mentoring to write up a cohesive grounded theory.

Karolina Bjernby Dufva, for the beautiful illustration on the cover of this thesis.

Marcela Sylvander for friendship and support writing popular science.

I would also like to thank all the colleagues who believed in this process, and especially my previous clinical managers:

Ditte Ljungman for the conversation on the balcony.

Tuija Peltonen for welcoming research at the clinic.

Seika Lee for encouragement in difficult times.

Bengt Larsson for teaching me the art of clinical medicine and for his continuous support over two decades.

And lastly, and firstly, my dearest husband Arvid and our beloved daughters, for together walking the path of life towards understanding and love.

10 APPENDIX

10.1 A FAILED INITIAL EFFORT TO TEST AN INTERVENTION IN PRIMARY HEALTH CARE

As good results were reported from the use of an intervention in psychiatry in Finland and Sweden, the initial plan was to test the effect and suitability of this intervention in PHC. Efforts began and lessons were learnt but there was not enough power to complete a randomized controlled trial. After the mid-way seminar, the research plan was therefore changed to exploring the theme of children as next of kin more openly by learning about implementation, conducting a systematic literature review, and exploring the main concern and strategies of children and parents in PHC.

10.1.1 The “Let’s talk about the children” intervention” in primary health care

The Beardslee Family Intervention (FI) was developed by Professor William Beardslee at Harvard Medical School, USA, for depressed parents and their children (16). Its long-term goal is to prevent children falling ill in depression. Short-term goals are to open conversations in families about the parental illness and increase that parent’s awareness of factors protecting the child’s development. It involves six sessions and one follow-up session. A short version “Let’s talk about the children” involves two sessions with only the parents. A Finnish study compared the long and short versions and found them to have equal effect after six months (109). The method was found to be applicable in psychiatry in Sweden where families report positive effects and the children describe a feeling of relief from worry over parental illness. (110-112).

10.1.2 The plan, effort, and lack of power

The initial plan was to include parents and their children and in a randomized controlled trial to test the effect of “Let’s talk about the children” on children in PHC. The effect on children was to be assessed using the Strengths and Difficulties Questionnaire (SDQ) both by parents and children. This questionnaire (113) reflects the child’s difficulties as well as their strengths, and targets hyperactivity/inattention, emotional symptoms, conduct problems, peer problems, prosocial behaviour and whether these symptoms affect everyday life. The SDQ is validated in Sweden for 14–15-year-olds (114). Power was calculated to 120 included parents.

From February 2014 to May 2017 intense efforts were made to include patients in the study. After three and a half years, only 27 parents had been included. These had filled out the SDQ on 41 of their children, 18 girls and 23 boys. Eighteen of these children, 5 girls and 13 boys, themselves filled out a self-rated SDQ. The small number of children scored by SDQ naturally generated power problems and limited the precision of the results, making proper statistical comparison with other studies irrelevant. For the sake of complete reporting of data, it is included below. In total, the data portrays the complex and multifaceted reality of PHC.

10.1.3 Learning from the attempt to conduct a clinical randomized controlled trial

Parents and staff who worked with “Let’s talk about the children” liked it. Seven nurses and psychologists at the clinic were trained to facilitate it. All enjoyed the training and giving sessions to parents. In total 14 parents were randomized to “Let’s talk about the children” and 7 of them did the two sessions. At the end of the second session parents were asked to give written feed-back on their experience. Six only had positive feed-back and one thought the invitation was a bit surprising.

It was concluded that preconditions for conducting a randomized controlled trial were not in place. There was not enough institutional stability to inform staff and include available patients in the study. This confirms learning from national investigations about the conditions of research in PHC. Obstacles to research were found to be lack of coordination and structures for research, lack of a research tradition, research not being part of the care job, production of care being in focus and what being what is encouraged, lack of leadership with high medical competence and academic thinking, and lack of finance (115). Furthermore, it became clear that the field was too unexplored, and it was uncertain whether the data collected reflected the most relevant data.

This experience and the mid-way seminar sparked an increased desire to learn what it would take to implement the intervention in PHC. During a course on implementation studies an analysis of what would be needed to implement “Let’s talk about the children” was conducted (section 10.2). It was found that the preconditions for implementation in clinical practise were also absent.

10.1.4 Results from the incomplete randomized controlled trial

A diverse study population: socioeconomically disadvantaged families

In a study population of 27 chronically ill parents, 23 women and 4 men, the median age was 45.0 for women and 43.5 for men. Sixty percent were born abroad. Eleven were born in Sweden, 2 in other European countries, 10 in Asia, 3 in South America and 1 in Africa. The mean number of years of living in Sweden was 28 (6–54), and mostly in Stockholm 23 (6–52). Forty-three percent had not completed nine years of basic schooling, 11% had university training. The self-reported mean number of months on sickness absence was 12, but the 75th percentile had been sick listed for 76 months, i.e. 6 years and 4 months. Thirty-nine percent did not cohabitate with their child’s other parent, and of those, 33% cohabitated with an adult other than the child’s other parent. Of 63% who spoke Swedish with their children, 23% did not speak Swedish themselves as children, as they were born abroad. The mean number of years of work in Sweden was 14 (0-30). Three parents had never worked in Sweden. Half of the parents were currently unemployed and had been so for a mean of about 3.5 years. In

Sweden, an unemployed person can be on sick leave and receive economic support if a doctor certifies a lack of functional ability. Self-reported reasons for sick listing were grouped into physical or psychiatric symptoms, 44% reporting solely physical symptoms, 30% both physical and psychiatric symptoms, and 26% solely psychiatric symptoms.

Emotional symptoms and impact: Results of the Strengths and Difficulties Questionnaire.

Results are reported in the table below. Girls self-reported higher scores than boys on all Strengths and Difficulties Questionnaire (SDQ) sub-scales and in total score. There were no significant differences between parents and boys in self-rated SDQ-scores. Girls rated their symptoms higher than their parents did. Parents scored boys higher on the hyperactivity and peer-relation subscale. Girls in this study population described more symptoms on all subscales than did to a community sample (114), except on the prosocial behaviour subscale. For boys in the study population, higher scores were identified on the sub-scales' emotional problems and conduct problems, and lower scores on prosocial behaviour problems, compared to the community sample. The SDQ scores of the study population are comparable with SDQ self- and parent-rated scores from a clinical sample of parents with substance abuse (116). Both parents' and children's scores indicated that the symptoms had little impact on the child's life.

	Self-report		**Parental-report**	
	Girls n=5	**Boys n=13**	**Girls n=13**	**Boys n=23**
	m (sd)	**m (sd)**	**m (sd)**	**m(sd)**
Emotional symptoms	5.6 (1.9)	2.7 (2.8)	4.4 (3.0)	2.8 (2.4)
Conduct problems	2.8 (1.3)	2.0 (1.6)	2.5 (1.9)	2.8 (2.3)
Hyperactivity/inattention	5.8 (2.6)	3.9 (2.2)	4.6 (3.0)	3.9 (3.4)
Peer relationship problems	3.8 (1.1)	2.6 (1.6)	2.3 (2.4)	3.1 (2.0)
Prosocial behaviour	8.4 (1.1)	8.1 (1.7)	8.4 (2.2)	7.8 (2.1)
Total problems	18.0 (4.3)	11.3 (6.9)	13.6 (7.1)	12.6 (8.4)
Impact	2.6 (1.9)	1.2 (2.6)	1.8 (2.7)	1.7 (2.8)

Table 5: Mean score and standard deviation of SDQ score, self- and parental report

10.2 IMPLEMENTATION OF AN INTERVENTION IN HEALTH CARE: AN EXAMPLE OF WHAT IT REQUIRES

The following report was produced by the author as part of a PhD course “Implementation research in health care”. It is included in this thesis as it illustrates the complexities of implementing a seemingly small and simple intervention in health care.

1. Description of Project

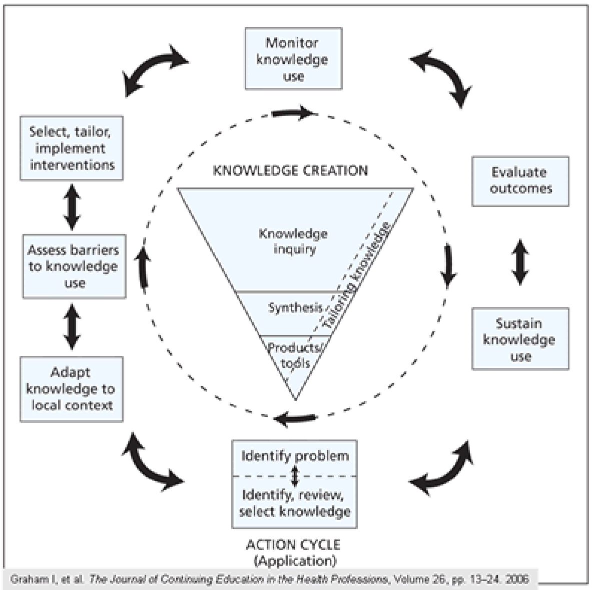
In Sweden health care professionals are by law required to consider the need of children to be informed of a parent’s severe physical or mental illness, substance abuse or sudden death (25). The intent is to protect the health and development of children. Interventions aimed at informing children of parental illness have been developed, and there is some evidence of effectiveness in cancer and out-patient psychiatric care settings (23). No studies have yet been conducted in primary health care (PHC).

In out-patient psychiatric care in Finland two interventions have shown a positive effect on emotional symptoms in children of depressed parents (59). The two interventions compared were the Family Talk Intervention and the substantially shorter “Let’s Talk about the Children” (LT), which involves two discussions with the parents. The focus of the present report is the latter, as a brief intervention to depressed parents, who are common in primary health care. The desired implementation outcome could be that 50% of parents with depression would be reached by LT within three months of diagnosis.

The aim is to analyse what implementation strategies it would take to make LT fill the need for suitable intervention in PHC.

2. Framework for Analysis

A process model aims to describe or guide the process of translating research into practice (117). The process model is a helpful tool for the implementation team rather than those who conduct the intervention. This paper will use the “Knowledge to Action” process model (118) as this model describes steps for both knowledge creation and a cycle where the steps needed to implement it are outlined.



Graham I, et al. *The Journal of Continuing Education in the Health Professions*, Volume 26, pp. 13–24. 2006

Figure 3. “Knowledge to Action” (Graham, et al., 2006) as presented in https://www.who.int/reproductivehealth/topics/best_practices/GREAT_image1.gif

3. Analysis

Identify Problem

Research and Swedish health care legislation identify that information about a parent's illness is the key to the child's continued healthy development. Currently, PHC personnel do not systematically address this need.

Determine the Know/Do Gap

There are laws, knowledge summaries (119) and practice guidelines in other areas than PHC (120). Key questions still exist in PHC:

a) In PHC, what illnesses do children need to be informed about? The law states "serious mental and physical illness as well as substance abuse and parental death" but what does that mean?

b) When should the child be informed?

c) What should the child be informed about?

d) How should the child be informed, i.e., by the parent, someone else, or a combination?

Identify, review, select knowledge

LT is chosen as it was shown to be effective and safe for parents with depression in a neighbouring country in outpatient psychiatry. Depression is common in PHC patients on long-term sick leave. Outpatient psychiatry resembles PHC practice, and there are no structural barriers to using LT in PHC.

Adapt to context

Depressed parents in PHC and in psychiatric outpatient care might be similar enough for the intervention to work in its original form. Patients in PHC might suffer from more frequent comorbidity but if the intervention is limited to depression, no adaptation of the intervention would be needed. Other challenges than depression might surface in the two conversations with the parents and an opportunity is needed to address these challenges later.

Assess barriers to and facilitators for knowledge use

In shifting an agency focus from an individual to a family perspective the importance of attending to workforce, organizational, and community capacities has been shown (121). The responsibility to initiate a conversation with the parent would then fall on the physician (GP) involved, often in cooperation with a psychologist or physiotherapist. Physicians in PHC are trained to be patient-centred in their work; this focus will facilitate implementation. It is critical to recruit and retain staff with a skill set for working with families. Lack of time and resources limit what even skilful physicians can do in relationship to an individual patient and his or her family. There is a need for regular, scheduled training in family-focused practice as well as practical help to meet challenges. Physicians may also lack confidence in their capacity to handle relevant conversations. They may have insufficient training and strategies for handling both psychological discussions and difficult home situations that might be revealed and warrant action. Furthermore, the leadership in PHC faces an acute lack of sufficiently trained staff and pressure from patient complaints, as well as demands from higher-level leadership, making them unable to provide sufficient leadership to implement a change of practice. There is currently a professional and political movement toward a national reform of PHC in Sweden (33).

Implement intervention

Implementation interventions would need to be put in place as preventive innovations diffuse rather slowly, in part due to delayed rewards from adoption (122) . The implementation intervention must be kept conceptually separate from the clinical intervention, in this case LT (123). Staff assigned as internal facilitators and managers at all levels should be engaged in realizing commitment, negotiating conditions, and keeping momentum going (124). The manager's leadership skills and behaviour will be critical for successful implementation (125). Implementation of policy is easy in name, but harder to transfer coherently into a workable tool (126). The choice of implementation strategies needs to be well considered.

Information at a staff meeting regarding the decision would focus on learning to honour this aspect of the profession. The need should be presented as based first on medical evidence, as medical professionals are motivated by the desire to provide high-quality professional care. It can be presented as a natural extension of the unit's patient- centred care and aim to prevent illness in the young. As a secondary benefit, this work also fulfils our legal responsibility.

To start using LT the staff need to attend a four-hour training seminar. Those trained then conduct a first LT and come back and reflect on experiences in a second four-hour seminar. The leadership should give group and individual feedback to the physicians so trained. There should be routines for how to handle difficult home situations revealed in cooperation with the leadership and other staff at the clinic such as nurses and psychologists, including reporting harmful situations to the social office under child protection law. No staff member should have to handle difficult situations alone, and therefore there needs to be time, emotional security, and practical possibility for professionals and leadership to handle difficult situations together.

Monitor knowledge use

The internal facilitator would need to support those trained to identify the first two patients to offer LT to. The LT sessions would need to be scheduled and the coordinator would need to reflect and give feedback to the newly trained.

Evaluate outcomes

The interventions would be reviewed after three, six, nine and twelve months to evaluate whether the implementation outcome of fifty percent had been reached. The following implementation outcomes have been suggested: acceptability, adoption, appropriateness, feasibility, fidelity, implementation cost, penetration, and sustainability (127). Those who have conducted LT, the coordinator and the leadership would meet to reflect on the outcomes in a qualitative way also after three, six, nine and twelve months.

Sustained knowledge use

The habit (128) of discussing the parental function with the patient when filling out a sick-leave form for depression could be helped by electronic or personal feedback. The individual physicians could also benefit from regular feedback on not only care of depressed parents and LT but on the total care of patients on sick leave: how they work with diagnosis and treatment, on the sick-leave administrative process, and on their task to inform the patient and their children about the illness. The outcome of this feedback would be mentioned in the physicians' annual developmental conversations and at the annual salary review. When LT is part of routine practice the staff would need an annual training and reflection gathering on the theme, to maintain and develop their practice. The internal facilitator needs continued time and support from the manager (129).

4. Conclusion

Using the knowledge to action (KTA) framework was helpful to get an overview of the action steps needed to implement LT in PHC. The framework's particular strength is that it specifies how knowledge creation and application are connected, which is helpful in a PhD project but not discussed in this paper.

When doing this analysis, the present author found that the guidance given in KTA on how to select, adapt and implement the intervention was too limited, and more structured guidance would have been helpful.

The analysis made it explicit how much leadership, training, coordination, and follow-up is needed to implement an intervention. Doing the analysis made clear that most PHC units are not currently set up to do what is needed to implement LT. Future work in this field requires both focus on creating high-quality PHC with staff stability and competent leadership, starting with knowledge creation.

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