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Home Care Services for Sick Children

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Family, healthcare and health-economic perspectives

CHARLOTTE CASTOR DEPARTMENT OF HEALTH SCIENCES | FACULTY OF MEDICINE | LUND UNIVERSITY Change will not come if we wait for some other person or...some other time. We are the ones we've been waiting for. We are the change that we seek

> Barak Obama February 5, 2008





Department of Health Sciences

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Home Care Services for Sick Children

Family, healthcare and health economic perspectives

Charlotte Castor



DOCTORAL DISSERTATION

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Abstract

Families with sick children often prefer home care to hospital care, and home care services (HCS) are increasing worldwide with limited evidence on how to provide high quality HCS in different settings. This thesis aims to provide a comprehensive view of HCS for sick children when provided by county-based HCS organized to care for adults and children.

A convergent mixed methods design with data-collection 2015–2019 was used. Phenomenographic analysis of interviews with 36 HCS healthcare professionals showed that caring for children was a challenging but rewarding task. Hermeneutic phenomenology was used to analyse 37 family member's lived experience of HCS as a possibility to strengthen family life and health when trustful alliances were built with HCS healthcare professionals. A review of referrals to HCS during a three-year period showed that 171 children with various ages, diagnoses and caring needs received HCS. Calculations of one year's healthcare costs for 32 children who received care both at the hospial and by HCS showed no increase in costs compared to estimated costs for only hospital care. Annual productivity losses due to 25 parents' absenteeism from work, estimated from questionnaire-based data, showed continued productivity losses during periods of HCS.

With trustful alliances between families, HCS and paediatric departments, cost-sustainable countybased HCS can be provided with high levels of family acceptability and positive effects on family life and health in sick children of various ages, illnesses and stages of illness. However, unequal accessibility and utilization may jeopardize care based on child and family needs.

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Home Care Services for Sick Children Family, healthcare and health-economic perspectives

Charlotte Castor



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"To every child and family who has enriched my life and broadened my horizons"

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Abstract

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Original papers

This thesis is based on the following papers:

- Paper I Castor, C., Hallstrom I., Hansson H. & Landgren K. (2017). Home care services for sick children: Healthcare professionals' conceptions of challenges and facilitators. *Journal of Clinical Nursing*, 00:1–10. doi.org/10.1111/jocn.13821
- Paper II Castor, C., Landgren, K., Hansson, H. & Hallström, I. K. (2018). A possibility for strengthening family life and health: Family members' lived experience when a sick child receives home care in Sweden. *Health & Social Care in the Community*, 26(2), 224–231. doi:10.1111/hsc.12512
- Paper III Castor, C., Hallström, I. K., Landgren, K. & Hansson, H. (2019). Accessibility, utilization and acceptability of a county-based home care service for sick children in Sweden. *Scandinavian Journal of Caring Sciences*, 1–9. doi: 10.1111/scs.12678
- Paper IV Castor, C., Bolin, K., Hansson, H., Landgren, K. & Hallström, I. K. Healthcare costs and productivity losses associated with county-based, home-care service for sick children in Sweden. *Submitted*

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Abbreviations and definitions

HCS	Home care service/-s
SCT	Special care task
PedsQL HS	Paediatric Quality of Life Health care satisfaction
PL	Productivity losses
STAI-Y	State-Trait Anxiety Inventory, version Y
State-A	State-anxiety
Trait-A	Trait-anxiety
Family	A social context consisting of at least two persons characterized by mutual attachment, caring, long-term commitment and responsibility ³⁵
Home care service	Community health and nursing service providing coordinated multiple services to the patient at the patient's home. HCS are provided by a visiting nurse, home health agencies, hospitals, or organized community groups using professional staff for care delivery and differs from home nursing which is provided by non-professionals ¹⁰²
HCS for children	Care that substitutes for acute hospital review and/or admission by providing clinical review, support, education and management of acutely or chronically unwell children in their own home ¹⁰⁶
Health	State of complete physical, mental and social well-being and not merely the absence of disease or infirmity ²²
Illness	Disease or period of sickness affecting the body or mind ²³

Life-limiting illness	Condition where premature death is common, for example, Duchenne muscular dystrophy ¹⁷
Life-threatening illness	A condition with a high probability of premature death due to severe illness, but also a chance of long-term survival to adulthood. For example, children receiving cancer treatment or admitted to intensive care after an acute injury ¹⁷

Introduction

Illness in a child may lead to difficulties for the family to maintain ordinary family life¹⁻⁴. Care at the hospital may further lead to decreased autonomy⁵, increased fear, sadness and worry⁵⁻⁷, and feelings of boredom ⁷ among children admitted to hospital. Siblings have expressed feelings of worry and of being left out when hospital admissions split the family⁸ and families often prefer care in the home to care at the hospital when a child is ill⁹⁻¹².

For this reason, international policy documents state that children should be admitted to hospital only when care cannot be provided at home¹³⁻¹⁵, and services for care at home for children with acute and long-term illness¹⁶ and palliative care¹⁷ have increased in recent decades. However, models for organizing, providing and financing home care service (HCS) for children vary internationally and within countries, and the evidence base for how to organize and provide high-quality HCS in different models is limited^{18, 19}. Each model brings its strengths and weaknesses, which limits transferability of knowledge from one model to another, and it is vital to identify aspects of importance for high-quality HCS in different models and contexts.

Provision of HCS, as a replacement and/or complement to hospital care for children in Sweden is organized in different ways and can be based in the community or at the hospital. Availability varies and can be limited to children with a certain diagnosis or condition. To increase accessibility and equality in care, a political decision in 2013 stated that all inhabitants in the county of Skåne should be offered HCS when in need of care. The county-based HCS was organized in the community to care for both adults and children regardless of diagnosis or prognosis, while scientific knowledge to support implementation of various models of HCS is still scarce.

This thesis reports observational studies on HCS for children provided by the countybased HCS organized to care for all inhabitants in the county regardless of diagnosis and prognosis. Mixed methods, combining qualitative and quantitative approaches, were used to provide a comprehensive view of HCS for children by exploring different perspectives of care. The findings are discussed in relation to the theoretical framework *Bowen family systems theory*²⁰ by Murray Bowen and the *Demand for health theory* by Michael Grossman²¹ and ends with clinical implications and suggestions for future research. This adds important knowledge on how to organize and plan HCS based on family and healthcare needs.

Background

Health and illness in childhood

The World Health Organization states that health is the "state of complete physical, mental and social well-being and not merely the absence of disease or infirmity"²². This implicates that both the illness, "a disease or period of sickness affecting the body or mind" ²³ and its consequences on life have a great influence on the possibility for optimal health. Illness can be divided into subgroups related to duration of illness; acute (rapid onset and duration less than one month), long-term (lasting at least 6 months) and chronic (persisting over a long period and affecting physical, emotional, social, or spiritual functioning)²⁴ or related to risk of death; life-threatening and life-limiting¹⁷ illness. Approximately 1,000-2,000 children are diagnosed with Lyme disease²⁵ and about 300 children 0-17 years of age, are diagnosed with cancer²⁶. Chronic conditions in childhood are complex and include includes many rare conditions such as cystic fibrosis, congenial hypoplastic anaemia, Duchenne muscular dystrophy, epidermolysis bullosa or haemophilia occurring in 2-10/100,000 children in Sweden²⁷ while childhood diabetes is more common among Swedish children with an incidence risk of 42/100,000²⁸. Furthermore, children have varying prerequisites for care and cure²⁹ and their socioeconomic situation, such as living conditions, adversely affects the risks of illness³⁰. Increased survival rates lead to an increased number of children living with a variety of life-threatening and life-limiting illnesses^{31, 32}. While the number of paediatric deaths in the western world is low it is still related to a number of different diagnoses with neo- and perinatal, neurological and oncological diagnosis being most common reasons for death^{33, 34}. In Sweden the prevalence of death before 18 years of age was 0.2% 2017 with highest risk of death for children below one year of age³⁴.

Everyday life and needs during illness

Craft and Willadsen describe the family as "a social context consisting of at least two persons characterized by mutual attachment, caring, long-term commitment and responsibility" ³⁵ p. ⁵¹⁹. This description is inclusive and fair in that many people with close relations to the child may be affected by illness in a child. In this thesis the spirit

of Craft and Willadsen is incorporated, but the word family will be used for the narrower group consisting of parents including legal guardians and siblings and other individuals living with the ill child part- or full-time. Other close relatives, schoolmates, neighbours, friends and so on, will be named accordingly.

When long-term or chronic childhood illness hits, children and families may experience loss of control and struggle to regain control and normality in their everyday life^{1, 36-39}. Children experience fear⁴⁰, that illness may disrupt their everyday life such as school attendance⁴¹ and affect their independence in day-to-day functioning and social life⁴²⁻⁴⁵. Illness may negatively affect parents' sleep quality^{46, 47} and impose a risk of negative impact on parents' mental health⁴⁸⁻⁵⁰, workload^{46, 47}, responsibilities⁵¹ and burdens^{52, 53}. Siblings may struggle with complex and contradictory feelings of protection and jealousy towards the ill child⁵⁴ and with upholding their everyday activities⁴¹. Through support from healthcare professionals^{38, 55, 56} as well as from family, friends and society such as school^{3, 43}, it is possible to lower some of the negative impact of illness trough out the illness trajectory and also for bereaved family members^{57, 58}. At the same time, experiences, feelings and needs in relation to illness and health also evolve over time^{42, 45, 59, 60} making the everyday life of a family with an ill child an ongoing struggle^{42, 49}.

When illness leads to hospital stays, it entails additional difficulties for the family to maintain ordinary family life^{1, 2} and may lead to social stigma⁶¹. Sick children may experience feelings of being lonely, sad, angry or bored^{7, 62} as well as increased feelings of fear and worry^{5-7, 61}, which contribute to impaired autonomy and sleep^{5, 63}. Children may long for companionship and protection⁷ and fear that their social life with school and friends will be negatively affected⁶². Siblings may struggle with being left out of family-related conversations and information about the illness⁶⁴ as they are often apart from other family members due to the hospitalization⁵⁴. Parents may feel vulnerable and insecure during hospitalization with their sick child when the hospital is experienced as unfamiliar⁶ and when the need for support from familiar, trusted healthcare professionals is not met⁶⁵. Parents may further suffer from poor sleep during hospitalization due to lack of trusted relief⁶⁵ and surrounding disturbances⁶⁶ such as slamming doors or unexpected visits in the room⁶³.

Thus, illness in a child brings many challenges and families may need support from the healthcare system while simultaneously endeavouring to reduce the impact of illness on well-being and everyday life. Families therefore often prefer home care to hospital care^{9-11, 67, 68} also for end-of-life-care^{12, 46}. This is supported by international^{13, 14}, Nordic⁶⁹ and Swedish¹⁵ policy documents stating that children's best interests should be catered for⁷⁰ and that children should be admitted to hospital only when care cannot be provided at home¹³.

Healthcare during childhood illness

Different frameworks for organizing and delivering care to children suffering from acute, long-term or chronic illnesses, and their families, have been developed over the years. The importance of parental participation in care to secure the child's emotional and physical well-being was approved in the second half of the twentieth century⁷¹. It was further developed into the well-acknowledged family-centred care approach including key elements such as building trust, listening to the concerns of the parents' and valuing parents' knowledge of their child⁷². The family centred care approach has later been criticized for being imprecise, misunderstood, insufficiently evaluated⁷³ and focusing on the parent rather than the child⁷⁴. To fully acknowledge the rights of the child⁷⁵ as an active participant in his or her own care, Coyne et al.⁷⁴ suggest a shift from a child perspective (articulated by parents and healthcare staff) towards a child's perspective (articulated by the child itself)⁷⁶. This moves the focus in care planning and delivering from that of the parents towards that of the child. The child-centred approach to care acknowledges the child as the key and active agent in the partnership. While belonging to a family and being guided by adults the child's care is planned around the child's perspective and preferences and is based on his or her needs and rights to privacy and dignity as well as competence⁷⁴.

Palliative and end-of-life care

WHO states that children with life-limiting and life-threatening illnesses are entitled to palliative care from the time of diagnosis and regardless of whether or not care directed towards illness is ongoing or not. Palliative care includes care for the whole family with a multi-professional approach and should be provided wherever the child is being cared for, including in the child's home¹⁴.

The need of support within this divergent group of children⁷⁷ differs considerably depending on diagnoses⁷⁸, the number of additional conditions⁷⁹ and throughout different stages of illnes⁶⁰. Still, children and families benefit from continuous integrated palliative care^{80, 81} as part of care throughout the child's trajectory of illness⁸¹⁻⁸⁴. The children's needs during life-threating illness and death not only differ among themselves^{78, 85}, they also differ from adult patients in several aspects^{33, 85-87}. For example, the spectrum of symptoms differs and children are shown to have longer periods of home palliative care then adults have⁸⁵, especially for non-malignant conditions⁸⁶. These differences may affect what service and competence is needed to provide high-quality care⁸⁷. Palliative healthcare services for children are increasing although the global distribution is uneven⁸⁸⁻⁹⁰, and they can be organized as care for children in hospital^{78, 91}, in hospice⁷⁸, at home^{85, 92} or as a mixed form⁹³. It can further be organized as care either for children alone⁹⁴ or for both adult and paediatric

patients^{95, 96}. When palliative healthcare services are organized to care for both children and adults, children will typically compose a minor group of the patients as childhood deaths account for 1/150 adult deaths in countries comparable to Sweden⁹⁷.

HCS for children with life-threatening or life-limiting should thus be organized, planned and carried out taking the child's needs and wishes, as well as the principals of palliative care, into consideration.

Swedish healthcare and social security systems

Healthcare system

In Sweden, healthcare for children is predominantly public. It is controlled and subsidized by state, counties and municipalities. State laws and regulations provide a foundation from which the supply of regional and local healthcare is organized and prioritized with partial self-governing among counties and municipalities⁹⁸.

Approximately two million children residing in Sweden⁹⁹ are offered enrolment in county-based primary child-healthcare services (0–6 years) and school-based child health services (6–17 years). County-based primary healthcare is further provided to children with acute, curable healthcare needs. Children who need specialized healthcare are mainly cared for at a local and/or university hospital.

Social security systems

The Swedish social insurance provides basic financial security to all families with children under the age of 18 through a system of insurances and allowances. Insurances include parental benefits of 480 days per child, to use from the child's birth, or adoption up until twelve years of age, when nursing a healthy child at home. One part of the insurance is a fixed amount and one part is income-related. A general child allowance (1,050 SEK/month in 2017) is paid to all families living in Sweden from the time of birth until the child turns 16. Temporary parental benefits are paid to parents who stay home from work to care for their ill child. The benefit makes up for approximately 80% of the benefit-qualifying income and can be paid for a maximum 60 days per year per child. When a child's condition is life-threatening or critical as assessed by a physician the maximum of days of temporary parental benefit is unlimited and can be utilized by two parents simultaneously. Families with a sick or disabled child with a need for long-term special supervision and care may apply for further care allowance¹⁰⁰.

Health economics

As available options for health-care treatments and services have grown more numerous, prioritization in the use of finite resources has become more complex. Health-economic evaluations are one important tool available to policy makers for making such prioritizations¹⁰¹. Health economics is concerned with questions related to individual decision-making related to health, and the consequences that those decisions have for the individual and society¹⁰¹. The methods for performing health-economic evaluations allow comparisons of two or more competing allocations of resources in terms of their costs and consequences. However, studies examining costs only also provide important information upon which policy makers base their decisions about how to use finite resources¹⁰¹. Such studies may involve both direct costs, such as healthcare costs, and indirect costs, such as productivity losses and family expenses.

Home care services

Historically and globally, home has been and still is a major scene for the care of sick family members, and other family members have often been the primary care givers also during long-term life-threatening or life-limiting illnesses and for end-of-life care. Various kinds of support have then been provided by the surrounding society. Medicine men, nuns, a single general practitioner, unpaid nurse or midwife is successively being replaced by modern professionally organized HCS¹⁰² for care in the home of the sick and there has been an increasing utilization of various models of HCS both internationally^{18, 103, 104} and in Sweden¹⁵. Palliative care services and care services for elderly people or people living with a disability more often involve or consists of HCS, while availability of HCS during acute or long-term illness is less common.

Home care services for sick children

HCS for children can be described as care that "substitutes for acute hospital review and/or admission by providing clinical review, support, education and management of the acutely or chronically unwell child in their own home" ^{105 p. 3}. Models for organizing, delivering and financing HCS for children are diverse and varies both internationally and within countries^{10, 105-107}, with varying extent of availability, resources and competence.

Different models of HCS can be distinguished according to where they are organizationally based¹⁰. Commonly HCS is based either in the hospital or in the community e.g. the county or the municipality^{10, 16, 105, 108}. HCS organized in the hospital tends to be diagnosis-specific, for example directed towards children with

diabetes¹⁰⁹ or cancer¹¹ or directed towards specific groups of children such as newly born¹¹⁰ or children at the end of life¹¹¹. HCS organized in the community is more often generic, e.g. accessible to a wider group of patients regardless of, for example, age or illness¹⁶ although there might further be several additional models of HCS not easily categorized in the above¹⁰.

Resource allocation to HCS for ill children varies greatly which leads to variations in accessibility from a few hours a day to a 24-hour service^{16, 105}. Furthermore, the level and extent of competence varies as HCS can be staffed in different ways, for example exclusively with nurses or with multi-professional teams including nurses, physicians and other allied healthcare professionals^{10, 112} While hospital-based, diagnosis-specific HCS tends to be provided by healthcare professionals experienced and specialized in paediatric care^{11, 109}, community-based HCS may be primarily staffed by healthcare professionals specialized in caring for adult patients¹⁵.

Home care services for sick children in Sweden

A national survey from 2008 showed that HCS for children in Sweden is limited and resources, competence and access are allocated in various ways throughout the country¹⁵. HCS can be provided both based in the hospital, staffed with healthcare professionals from the paediatric department, or outside the hospital either in the county or the municipality. Neither of these services has been thoroughly researched and especially studies on Swedish generic HCS based in the county and organized for both children and adults are lacking.

Family perspectives

HCS can support families in their struggle for a calmer and more normalized everyday life^{113, 114} as care can be given without disruption of hospital stays¹¹³⁻¹¹⁶ and thus facilitates school attendance^{113, 114}, work attendance¹¹⁴ and allows the whole family to be together¹¹⁷ also at the end of life⁴⁶. Studies show how HCS can be provided with overall high parental satisfaction^{11, 109}. A well-planned transfer from hospital to HCS¹¹⁸, well-established relationships between family and HCS healthcare professionals⁹, and a high level of competence among HCS healthcare professionals¹¹⁵ with the ability to interact and respond to the child's needs¹¹³ are important for parents to feel satisfied with HCS. In addition, a few studies find that a lack of established relations with HCS healthcare professionals may lead to lower confidence with HCS⁹, and a sense of lack of communication⁹ or inadequate competence among HCS healthcare professionals¹¹⁹ may lead to insecurity among parents. Receiving HCS may further increase the medical responsibility placed on parents^{9, 120}. Stevens et al. describe increased levels of parentreported distress in their child when receiving HCS from community nurses¹²¹. The transfer from hospital to home has been identified as challenging and it is important for families to be prepared before discharge in order to feel safe^{120, 122}. Most studies on families' experiences of HCS take a child perspective through parent's experiences rather than the child's own perspective. Family members' needs are complex and not always coherent. Furthermore, according to the Swedish Patient Act⁷⁵ and the UN Convention on the Rights of the Child⁷⁰ children have the right to participate in decision-making concerning their own care and in research on matters that concerns them. Thus, further research is needed on HCS for sick children, including the child's perspective.

Healthcare professionals' perspectives

Providing HCS for children may constitute a challenging and demanding task for HCS healthcare professionals. HCS healthcare professionals often care for adults but may be less experienced in the care of sick children^{15, 16, 96, 123, 124}. This may lead to passionate involvement from healthcare professionals¹⁰ and also challenging feelings of inadequacy and vulnerability among HCS healthcare professionals have described HCS for children as time-consuming and it may thus be demanding to find resources¹⁰ and identify a structured way to carry out care for this rare group of patients¹²³. A trustful relationship with the families and confidence in their own professional role were helpful prerequisites for healthcare professionals¹²⁴. Even though utilization of HCS for ill children is increasing there is still limited scientifically based understanding of prerequisites and experiences from a healthcare professionals' perspectives.

Health-economic perspectives

The organization and financing of HCS differ between healthcare systems¹²⁶, which makes the scope for comparisons between, and generalizations from, different evaluation studies limited¹⁰⁵. Parker et al.¹⁸ concluded in a review of randomized HCS studies that the evidence regarding the effects of HCS on healthcare costs and on the financial situation of affected families is emerging but limited and, further, that the findings are conflicting¹⁸. This is confirmed in a Cochrane review from 2013, in which the authors call for further health-economic research including various models of HCS¹⁰⁵.

Most HCS studies which include health-economic perspectives focus on healthcare costs. Some studies have found that healthcare costs may decrease when care is given in the family home instead of in the hospital¹²⁷⁻¹²⁹. Other studies have found that effects on costs for palliative care are related to the child's diagnosis¹³⁰, the type and extent of HCS that is provided and how well the service is utilized¹⁶. For instance, home care limited to hospital-based daytime nursing services from the paediatric oncology departments was associated with lower total healthcare costs than would have been the case for corresponding healthcare provided as inpatient care and on a par with

outpatient daycare¹¹. Dried blood spot sampling at home compared to conventional blood sampling at the hospital was associated with decreased healthcare costs by 7% for children with haemato-oncological illnesses and 21% for children with nephrological illnesses. However, cost savings varied due to the number of hospital visits that could be avoided by home blood spot sampling¹²⁷. Enrolment in a palliative home care programme did not reduce the number of admissions to hospital but reduced the length of the stay. This led to reduction in hospital costs, especially for children with other illnesses than cancer¹³⁰. Contrariwise, home versus hospital breastfeeding support was associated with increased healthcare costs after discharge compared to when support was given at the hospital¹³¹.

Research focusing on the association between HCS for sick children and a societal perspective is scarce today. Some studies report a significant reduction of productivity losses when the number of hospital visits was reduced^{18, 127, 129}, while another found limited or no effects in long-term productivity losses when children with newly diagnosed diabetes received care in a family-friendly home-like environment outside the hospital¹²⁸.

No significant impact on family economy has been proved^{53, 128, 131} though some family expenses, such as driving expenses, might be reduced when hospital stays can be lowered^{127, 132}.

Thus, HCS constitutes a complex healthcare service and further studies are needed on different models of HCS to increase knowledge on such issues as usage^{105, 107}, care needs related to various diagnoses and care tasks¹⁰, resource utilization¹⁶, referral characteristics from hospital to HCS^{10, 133}, communication¹³³ and family preferences for different models of HCS¹⁰⁵.

Theoretical framework

The child's diagnosis, illness trajectory and care needs, the family's socioeconomic situation and the family composition may affect family members emotionally, psychologically and socially both during and after periods of HCS. Furthermore, HCS concerns and affects healthcare professionals providing care for the child and the larger society in which the family lives and in which HCS is planned and financed. To embrace these multiple aspects, two theories are used as a theoretical framework in this thesis. Bowen family systems theory²⁰ is used to deepen the understanding of families' experiences and needs during HCS and of the interacting of family functioning and provision of HCS including the role of HCS healthcare professionals. Demand for health theory²¹ is used to further understand choices made by families with ill children receiving HCS to optimize everyday life and health among family members in both a

short-term and a life-time perspective and how HCS and HCS healthcare professionals influence these choices.

Bowen family systems theory

Murray Bowen's theory of family systems emerged during a paradigm where the psychology of the individual was directorial, typified by Sigmund Freud¹³⁴. The theory is rooted in the assumption that there is more to an individual's relatedness to life than a psychological construct of individuals. Further, understanding of the human emotional functioning and behaviour must include studies/theories on relationships with other individuals²⁰. The theory states that "the family is a system in that a change in one part of the system is followed by compensatory change in other parts" or rather not one but several systems as "the family is a variety of systems and subsystems" ²⁰ p. ³⁵¹. The family is seen as an emotional, naturally occurring system that has evolved over millions of years. Bowen merges this insight with the insight of knowledge drawn from empirical studies on how families respond to tension. The family uses successful or less successful strategies to cope with the given tension¹³⁴ that can be induced, for example by illness in a family member and corresponding care needs.

Each individual has a certain capacity to make self-directed choices and thus functions autonomously (differentiation) alongside a capacity to fuse with others as a reaction to a tension. Constant processes of the individual's balancing between differentiation and fusion serve to achieve harmony within the systems¹³⁵. A system of three individuals is seen as the smallest stable relationship system in the Bowen family systems theory. When emotional tension rises within a system, a triangle is more sustainable as it can shift focus on relations within the triangle, allowing the triangle to contain more tension than the dyad. Relationship fusion within the triangle serves as the fuel in the emotional process, for example during a couple conflict, illness in a spouse or projection of the problem onto a child in the close nuclear, single-generation family¹³⁵. Constant fusions of deep emotional feelings, attitudes and values further alter the level of differentiation passed from generation to generation in an automatic, predictable and regular process of multigenerational triangles. Triangular fusions involve siblings, where Bowen finds the sibling positioning in a family more important than gender or ethnicity as it predicts some main characteristics in that individual. However, siblings can shift psychological characters or positions¹³⁴. Similar fusions can further be seen in relation to a society such as a healthcare service and further on, a nation. For example, a workplace or nation can go into regression as a response to a tension on a societal level, just as a family can respond with withdrawal to tension in the family¹³⁴. Illness in a child can lead to extra tension for a child born in the same position in the next generation, due to other family members' view of him or her as more vulnerable¹³⁵. Triangular fusions are also instrumental in creating emotional tension as the individuals involved react to the fluctuating relationships of two being inside and one being outside. When tension increases it can be spread between interlocking triangles in order to be stabilized. Unresolved emotional issues with parents, siblings, other family members or society can be managed by reducing or totally cutting off emotional contact, affecting future generations in a process related to the level of differentiation¹³⁴.

Anxiety, described by Bowen as an emotional process and present in all living humans, is central in the Bowen family systems theory which focuses on patterns that develop within families to control anxiety^{134, 135}. It is a response to actual (acute) or imagined (chronic) threat with a clear distinction between the two. While acute anxiety is time-limited, chronic anxiety may continue for an indefinite time. Levels of anxiety are influenced by many things and not caused by only one factor. Both inborn and learned elements play a role in all anxiety, although learning plays a more important role in chronic anxiety response. The experience of stress, an emotion related to anxiety, varies through generations in an individual and in a family unit as levels of differentiation decrease or increase. Different events, such as illness in a child, act as stressors which in turn trigger anxiety and increase tension¹³⁴ within one or more interlocking triangles. Thus family members' reactions are driven by previous experiences within themselves or other closely related persons when a child is ill and actions are taken as a response to these reactions, aiming at stabilizing tension. In turn, with stabilized tension, the individual's possibility to making health-related self-directed choices increases.

Demand for health

Gary Becker first developed the idea of human capital with education as the principal component¹³⁶, which was then extended by Mikael Grossman²¹ to include health as the other principal component of the stock of human capital. Educational capital is accumulated during a person's life, starting out with no capital at birth. In contrast, health capital is partly inherited, but may, as is the case with educational capital, be added to by individual investments. In fact, some investments are eventually required in order to maintain good health as the health stock deteriorates over time. The key notion in the demand for health theory is that the individual produces investments in his or her health by combining own time with healthcare goods and services. Moreover, health is demanded for two reasons: it increases the amount of time being healthy that can be used for productivity purposes, which is often referred to as the investment property of health. The consumption property is the utility that is derived from being in good health¹³⁷. Thus, observable individual health-related behaviour is determined both by individual characteristics, such as preferences for good health and attitudes towards risk, and by available resources. Family members receiving HCS due to illness in a child thus make individual considerations leading to different decisions and actions in order to maximize their health. Grossman's original formulation of the demand for health model²¹ was developed for a representative individual. The model has been extended in order to include the family as the decision-making unit¹³⁸⁻¹⁴⁰. Not only

choices made during adulthood but also during childhood affect an individual's human capital, and the demand for health theory can be applied in a life perspective¹³⁸. Furthermore, Jacobson notes that people both influence and are influenced by other relatives in accordance with Bowen's family systems theory, which makes imprints in their health-related choices¹³⁸. Jacobson shows that an adult cohabitant with another adult makes choices based on what benefits not only their own health but also the other's. This mechanism is valid also when the family includes a child, as with families in this thesis. Parents are willing to sacrifice monetary income to stay at home to care for an ill child and do not only do this for altruistic reasons but also as a way to invest in health¹³⁸. However, the socioeconomic situation of a family affect the possibilities of the parents to invest and, for example, parents with own illness might have disadvantageous relative to healthy parents when it comes to the capacity to make health-related investments¹³⁸. Care in the home might affect family members' possibility to act and influence their everyday life both during and after the period of HCS. Therefore, the demand for health theory constitutes a complement to the Bowen family systems theory when understanding families' experiences and choices during and after HCS and is relevant to studies on HCS for sick children.

Aims and objectives

The overall aim of this thesis was to provide a comprehensive view of HCS for children provided by county-based HCS organized for adults and children, from different perspectives. This thesis is based on three studies reported in four papers. The specific aim of each paper was:

- I To explore healthcare professionals' conceptions of caring for sick children in HCS.
- II To elucidate family members' lived experience when a sick child received home care from county-based HCS.
- III To (i) determine characteristics in referrals to county-based home care, (ii) determine characteristics of referred children and (iii) assess the acceptability of parents and children in county-based HCS.
- IV To estimate the healthcare costs and productivity losses associated with countybased HCS for sick children.

Method

Design

Convergent mixed methods

In this thesis qualitative methods (papers I & II) were merged with quantitative methods (paper III & IV) in a convergent mixed methods design to deepen and broaden the knowledge of HCS for children. Mixed methods design was developed as a framework for integrating qualitative and quantitative research during the 1980s and 1990s and is a suitable rationale when seeking a more complete understanding of complex research questions¹⁴¹ such as new models of HCS. Combining the two research approaches with different ontological foundation minimizes the limitations of each approach and provides a complex picture of the phenomenon that is being researched. In the convergent mixed methods design equal value is given to both approaches with the assumption that qualitative and quantitative data provide different types of knowledge. Studies with separate specific aims, data collection and analysis are carried out parallel but independently. Findings are then merged to let findings confirm or contradict each other and finally interpreted to provide a comprehensive view of HCS (Figure 1)¹⁴¹.



Figure 1. Overview of convergent mixed methods design (Cresswell & Cresswell, 2018)

This thesis includes three studies and various methods of design and data collection (Table 1).

Table	1.	Study	overview
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Study	Design and analysis	Population	Data collection	Paper
1	Inductive qualitative phenomenographic	Healthcare professionals in HCS	Semi-structured focus group interviews	Ι
2	Cross-sectional descriptive and comparative	Parents of children provided with HCS	Medical journal review	III
3	Observational descriptive and comparative follow- up + inductive qualitative hermeneutic phenomenological	Children receiving HCS and their parents and siblings	Administrative healthcare systems, Swedish southern regional healthcare pricelist and "cost per person" database Semi structured interviews Questionnaires	II, III and IV

Data collection and analysis followed a phenomenographic approach to explore HCS healthcare professionals' conception of caring for a sick child. Phenomenography finds its reason in people's conceptions of the world around them as they experience and understand it^{142, 143}. It is expressed in a second-order perspective focusing on how a phenomenon is conceived¹⁴⁴. Conceptions vary qualitatively between and within people in a finite and interconnecting scale of reality^{142, 143}, which allows it to be captured, described and communicated¹⁴⁴.

A hermeneutic phenomenological approach was followed to collect and analyse the meaning of family members' lived experience of HCS when a child is sick. Van Manen¹⁴⁵ describes the phenomenon as revealing itself in four existentials: lived body, lived space, lived time and lived human relations. Hermeneutics relates to the interpretation taking place throughout the process of data collection, analysis, writing and rewriting the lived experiences, while phenomenology relates to how the phenomenon reveals itself. Hermeneutic phenomenology seeks to find, and put into words, the essence of the families' lived experience¹⁴⁵.

A cross-sectional design was used to determine characteristics in referrals and of the children referred to county-based HCS. The cross-sectional design is descriptive and aims to provide data on the entire population of interest for a specific period of time¹⁴⁶.

The opportunity cost concept was applied to estimate societal costs, the opportunity cost of a specific use of resources being the value of the best alternative given up. The

human-capital approach was used to measure productivity losses as the reduction in the amount of time supplied to the labour market. The value of these productivity losses was measured as the number of changes in time worked times the value of each unit of time¹⁰¹.

A quantitative content analysis was used to assess parents' and children's acceptability of county-based HCS. The analysis consists of a stepwise, systematic process for collecting and analysing data from any type of communication such as written responses to open-ended questions¹⁴⁷.

Study context

The studies were performed in the southernmost county of Sweden. The county has a total population of approximately 1.3 million, of whom 300,000 are children 0-18 years of age with 64 paediatric deaths yearly⁹⁷. Paediatric healthcare in the county is delivered by one university hospital and two local hospitals with approximately 13,000 inpatient admissions yearly, supplemented by extensive care at several outpatient departments in the county. Until 2013, provision of HCS was limited and mainly organized as end-of-life care for adult patients. In 2013, the county council decided to offer all inhabitants in need of HCS, regardless of diagnosis, condition, stage of illness and age, and thus including children, provision of county-based HCS. The HCS, based in eight units, offers a 24-hour nursing and physician service, supplemented in the daytime by a multi-professional team consisting of counsellors, associate nurses, physiotherapists, occupational therapists and dieticians. The HCS units supply palliative home care, in which they have the main responsibility of care for the patient. The HCS further supplies specified care tasks (SCT) during limited periods of illness. Such SCT can be an administration of intravenous antibiotics by a HCS nurse prescribed by the hospital physician who also maintains the medical responsibility during care in the home.

Study population

Different populations from the same setting were included to encompass different perspectives¹⁴¹ of HCS for children in the studies, including HCS healthcare professionals (Study 1), all children referred to HCS (Study 2) and ill children receiving HCS and their family members (Study 3) (Table 1). Each of the eight HCS units in the county appointed a healthcare professional in the staff to assist in recruitment and correspondence with the research group.

Healthcare professionals within home care services

HCS healthcare professionals from each of the eight districts constitute the population in Study I. Inclusion criteria for participation were healthcare professionals, regardless of profession, who had cared for, or were expected to care for, sick children in HCS. To achieve a purposeful sample with maximum variation and information-rich data¹⁴⁸, healthcare professionals with different professions, age, work experience and gender were included. A total of 380 healthcare professionals were asked, by e-mail, to participate in one of nine prescheduled focus group interviews. Thirty-eight (38) healthcare professionals volunteered to be interviewed two of whom were unable to attend any of the scheduled meetings. Thirty (30) of the 36 participants were female and six were male. The participants' work experience in HCS varied from three months to 18 years (average 8.4 years). Six of the healthcare professionals had cared for more than five children in HCS, 12 had cared for three to five children and twelve had cared for one or two children. Six participants had no experience of caring for a child.

Children referred to home care services

Children aged 0–17 years, who were referred to one of the eight HCS units from April 2015 to March 2018, composed the sample used to determine characteristics of referrals and referred children in Study 2. Eligible children were identified from the hospital administrative system by administrative staff.

Children receiving home care services and their family members

Children who received HCS, their parents and siblings composed the sample for Study 3. Inclusion criteria were parents with sufficient ability to speak and read Swedish as assessed by HCS healthcare professional, and place of residence in the county. The study contact person at each HCS unit was asked to forward brief information about the ongoing study to eligible participants and supplied the research group with contact information to parents who chose to participate. Parents of 48 ill children agreed to receive detailed oral and written information on the study and family members in 36 families contributed data in one or more parts of Study 3 (Table 2).

Study	Sample	Data collection	Presented in
1	36 healthcare professionals	Seven semi-structured focus group interviews	Ι
2	204 children	Medical journal review	III
3	12 families including: 4 children, 23 parents and 10 siblings	15 semi-structured family interviews	II
	Parents of 23 children	Acceptability questionnaires	III
	51 parents	Demographic questionnaire	IV
	32 children	Administrative systems Swedish southern regional healthcare pricelist and "cost per person" database	IV
	37 parents	PedsQL HS STAI-Y	Thesis

Table 2. Detailed view of study sample and data collection

Parents

Fifty-one parents completed one or more questionnaire and composed the sample to assess acceptability, productivity losses, healthcare costs, anxiety and/or healthcare satisfaction.

Sick children and family members

A purposeful sample of fourteen families with a child who received HCS received written and oral information about the interview study. The families were chosen to capture experience from both SCT and palliative care and a variation in children's diagnoses, ages, family conditions, living area and ethnicity¹⁴⁸. In total 12 families including 12 mothers, eleven fathers, ten siblings and four ill children participated in one or two interviews (Figure 2). The children's diagnoses included cancer, chronic lung disease, congenital hiatal hernia, heart disease, and Lyme disease and they were aged six months to a median age of 3.5 years.



Figure 2. Overview of time of interviews in relation to HCS, type of HCS and length of HCS provision

Data collection

Data collection started simultaneously in March 2015 for all studies (Figure 3) and carried on according to each separate data collection plan.



* Data collection in Study 3 consists of three parts: ^aFamily interviews were performed between December 2015 and February 2017; ^bquestionnaries were administered from March 2015 to 2019 (including one year follow-up for each family) and ^cmedical journal review was performed in 2018-2019.

Figure 3. Data collection period.

Interviews

Focus group interviews

Seven semi-structured focus group interviews¹⁴⁹ with four to seven informants were moderated by the first author and assisted by a co-author and in one interview a research fellow. Each interview started with a call for participants to share conceptions about the first time they cared for a child at home or heard about the decision that children were to be offered HCS and thus were potential patients to care for in the future. A brief interview guide (Appendix 1a) and follow-up questions like "Can you explain more?" or "Can you give an example?" were constructed by the research group and used in all interviews. Interviews were digitally recorded and transcribed verbatim.

Family interviews

Each family chose the time and place for the interview, and decided which family members would take part. Before the interview family members were encouraged to take photographs of situations related to HCS. The technique of using photographs or pictures during an interview to enhance participation^{150, 151} turned out positively in a pilot interview in a setting similar to the study setting but with photographs taken beforehand by the researcher. None of the families in the study, however, took photographs specifically for the interview, although some showed other photographs. Each interview started with an introduction to the study followed by an invitation to all participants to narrate experiences of HCS with the interviewer. During the interview, a brief interview guide (Appendix 1b) was used and efforts were made to include all participants. For example, follow-up questions like "Tell me how this was for you" or "Do you recognize what dad just told me?" were used.

Questionnaires

Four different parallel questionnaires were administered by mail to parents at five time points during the observation period, namely the initial period of HCS (T1) and again after 1, 3, 6 and 12 months (T2–T5). Parents completed the forms and returned them by prepaid mail. Data were coded with the use of a code key and transformed into SPSS data files.

Acceptability questionnaire

Data on acceptability were collected by a questionnaire developed in a study on children receiving paediatric oncology HCS in Denmark¹¹. Parents were asked to rate their overall experience of HCS, how safe they felt, and how satisfied they were with HCS. They were further asked to rate their perceptions of their child's overall experience of HCS, feeling of safety and satisfaction with HCS. Ratings were collected after each visit by a five-point scale ranging from not at all to very much. Parents finally scored their family's preference for future care as yes or no to HCS. The questionnaire provided extra space to write comments in free text. The original questionnaire was tested for clarity and relevance by HCS nurses and thereafter for face validity by five parents and was deemed complete and simple to understand, in a study of HCS in paediatric oncology patients in Denmark¹¹. The first and last author of Paper III, who are both bilingual in Danish and Swedish, translated the questionnaire forward and back with the emphasis on conceptual translation and natural language¹⁵². The Swedish version (Appendix 2) was tested for face validity in a Swedish nursing research group.

Demographic questionnaires

Demographic data on the ill child, siblings and parents were collected by a designated questionnaire (Appendix 3a–d). Parents were asked to supply data such as age, parental education and occupation, number of adults in the household, earned before-tax income before and during the child's illness for parents, work absenteeism for parents and relatives who helped out with the care of the child, ill children's school attendance, illness-related effects on everyday life and progression of illness.

Psychometric instruments

STAI-Y

The State-Trait Anxiety Inventory (STAI) was used to rate parents' anxiety levels at five time-points during one year of observation. Theoretically, anxiety can be seen as a phenomenon divided into two related but different constructs¹⁵³⁻¹⁵⁵ The inventory was developed in English in the 1960s to measure anxiety levels in high school and college students¹⁵³ and has since then been revised and tested for a range of situations. The State Anxiety (State-A) scale relates to how an individual feels in a particular situation or in a certain place and the Trait Anxiety (Trait-A) scale relates to an individual's
relatively stable tendency to perceive situations as being threatening¹⁵³. The State-A and Trait-A scales in the present version STAI-Y, can be used as two independent scales with the two-factor construction confirmed by factor analysis¹⁵⁶. The two scales each consist of 20 items with a weighted score on a Likert scale where 1=not at all/almost never, 2=somewhat/a little, 3=moderately so/often, 4=very much so/almost always. For ten items on each scale, high ratings indicate high levels of anxiety and for the remaining items high ratings indicate absence of anxiety and a scoring key is provided to weight the scorings appropriately. Each scale can produce a total score from 20 to 80 with higher scores related to higher level of anxiety¹⁵³. Norm levels vary in relation to age, gender and educational level and no cut-off point for high or low anxiety is defined¹⁵³. Spielberger presented high internal consistency with Cronbach's alpha levels at $0.89-0.96^{153}$, consistent with a review of reliability generalization showing Cronbach's alpha mean for State-A at 0.91 (0.65-0.96) and for Trait-A at 0.89 (0.72-0.96) with age, score variability and research design as predictors¹⁵⁷. A Swedish translation of State-A administered to adult, healthy citizens in the capital showed Cronbach's alpha 0.92. STAI-Y has been used in recent research to measure anxiety levels among parents with ill children without further reliability or validity tests for the population^{52, 158, 159}, while additional psychometric evaluations have to a high extent been made on other versions of the inventory^{153, 157}. The present sample shows Cronbach's alpha for State-A at 0.96 and for Trait-A at 0.85.

PedsQL Health care satisfaction

The PedsQL Healthcare satisfaction (PedsQL HS) was used to measure parent's level of satisfaction with healthcare services. The instrument was developed to provide a standardized evaluation that might facilitate improvements in care delivery for children with haematological or oncological illness¹⁶⁰. Based on a literature review, a preliminary instrument, emphasizing the emotional aspects of satisfaction rather than only relationships with medical staff and organizational aspects, was developed. It was tested for content validity and reversed in several steps. The final instrument included 24 items in six domains: information, inclusion of family, communication, technical skills, emotional needs and overall satisfaction, although a four-factor solution was suggested in a component analysis with orthogonal rotation¹⁶⁰. Each item was rated on a 5-graded scale from very dissatisfied to very satisfied. Raw scores for each domain were linearly transformed into a 0-100 scale where 0=0, 1=25, ... 4=100. Domain scores were computed if 50% or more of the items in the domain were completed. Mean scale score= sum of computed domains divided by the number of domains¹⁶⁰. The Swedish translation, used in this thesis, was made by two nursing researchers using a forward and back method. The translation was then tested for face validity by teachers in healthcare and by parents of ill children in a version modified for investigation during hospital care¹⁶¹. Mean Cronbach's alpha for the present sample was 0.91.

Medical journal review

Designated SPSS files were constructed and used to collect data such as age, sex, diagnoses, source of referral, indication for referral, time from referral to initiation of HCS, duration of HCS in days, number of HCS visits, reasons for denial of referral and for premature discharge from HCS from medical journals and administrative systems on children referred to HCS.

Data were anonymized for children who were referred to HCS except for children included in Study 3. Data for these children were coded.

Analysis

Phenomenography

The phenomenographic structured analysis followed the seven steps described by Dahlgren and Fallsberg¹⁶². In the first step, all four authors aimed for familiarization by reading the transcriptions. In the second step, the first and the last author individually conducted condensation of statements and, in a third step, the authors compared these statements together. Thereafter, statements were grouped and preliminary categories of conceptions were articulated by the first and last author. Through discussions with all the authors, the preliminary categories and their internal relationship and borders were discussed and revised several times and description categories were established. In the final step, the categories were labelled and organized¹⁶² and the internal relationships were described¹⁶³. The findings were supplemented with quotations chosen to illustrate conceptions of HCS healthcare professionals caring for a child.

Hermeneutic phenomenology

The hermeneutic phenomenological analysis started with a naive reading of the transcribed interviews including memos by all four authors who thereafter reread the text independently. Phrases and paragraphs that revealed the family members' lived existentials, in terms of lived body, lived space, lived time and lived human relations, were identified by co-authors independently¹⁴⁵. Each existential was marked with a colour code to elucidate the lived existentials in each transcribed interview. In the next step, the authors compared the identified existentials to arrive at a deeper understanding of the family members' lived experience. The structure of their lived experience was then merged into preliminary subthemes and further on to essential themes. The first author started the process of writing, and all the authors discussed the relation between "the parts and the whole" following the hermeneutic spiral, to create depth in the family

members' lived experience of receiving HSC during the process of writing and rewriting¹⁴⁵. Quotations were chosen to make the family members' lived experience comprehensible¹⁴⁵.

Quantitative content analysis

Quantitative content analysis was used to analyse free-text comments in the questionnaire assessing parents' and children's acceptability. Categories of comments were identified according to content. Each comment was assigned to one or more category. Each category then was labelled and the number of times a category was involved in a comment was summarized, inspired by Kondracki et al.¹⁴⁷. The preliminary analysis performed by the first author was verified by a second author followed by adjustments on single comments for full agreement.

Statistical analysis

Healthcare costs, for the given and for the alternative care, were calculated as the number of physical units of healthcare utilized times the unit prices. Healthcare utilization for care at the hospital as a replacement for palliative HCS was estimated as one weekly day-care visit up until one week before the child's death and one week of inpatient care for the last week of life. Estimated productivity losses were calculated for parents who reported data for two or more observations and missing data on work absenteeism was replaced by the average of two available adjacent time points. When a child died, productivity loss for the first month was calculated as 100% and for the remaining months as 50% for mothers and 40% for fathers¹⁶⁴. The observed wage rate was multiplied by 1.5 in order to account for labour taxes.

Descriptive statistics were calculated. Nominal and ordinal data were expressed as frequencies (%) while interval and ratio data were expressed as median [interquartile range (IQR)] (minimum-maximum) or mean (standard deviations (SD)). Comparative statistics were analysed according to Table 3. Significance level in all analysis was set at p<0.05. Analysis was conducted using IBM SPSS Statistics 23 and 25 Windows (IBM Corporation, Armonk, NY, USA).

Table 3. Overview of statistical analysis

Study	Outcome variable	Test
II	Significance test of differences between units regarding indication for referral to PPC intravenous antibiotics	Fisher's exact test
II	Significance test of differences in distribution of diagnosis among HCS units	Fisher's exact test
II	Significance test of differences between HCS units regarding acceptance rate	Fisher's exact test
III	Significance test of differences in productivity losses and value of productivity losses between mothers and fathers rate	Mann-Whitney U test

Merging of the findings

Once separate analyses of data were performed and findings were described (papers I– IV plus thesis), an integration took place with the aim of merging the results of all three studies. Findings that confirm, contradict or in other ways relate to each other were identified and presented reconciled under headings, also emphasizing the coherence with the theoretical framework (Figure 4). In a final step, findings were interpreted and discussed in relation to the theoretical framework of this thesis, thus searching for a comprehensive view of HCS for children. Following convergent mixed methods design, the merged findings are presented in the Findings section and the interpretation is presented in the Discussion section of this thesis¹⁴¹.



Figure 4. Merged findings

Preunderstanding

Van Manen describes how the problem of phenomenological inquiry might not be that we know too little but rather that we know too much¹⁴⁵. This unreflected knowledge makes us at risk of predisposed interpretation of the phenomenon before we even come to grips with the significance of the phenomenological question. It is not possible to put aside everything that we know; instead we can make our understandings, biases and assumptions explicit and deliberately expose their concealing character¹⁴⁵.

The author of this thesis has been a paediatric nurse and worked with seriously ill and dying children for 25 years. She has some experience of home visits to ill children due to her work as nurse consultant in paediatric neuro-oncology and was familiar with the HCS yet having no experience of HCS work. The supervisors and co-authors have extended and broad experience in different fields of nursing and research, two within HCS research and two without. Furthermore, we are all parents. This ground for pre-understanding was repeatedly reflected upon and discussed throughout the work to gradually make way for an understanding of the phenomenon under study.

Ethical considerations

The Declaration of Helsinki

The research in this thesis followed the ethical principles for medical research involving human research in the *Declaration of Helsinki*¹⁶⁵. When performing research on humans ethical, legal and regulatory norms and standards must be considered. Research findings must never stand above the rights and interests of the research person but be carried out while protecting "the life, health, dignity, integrity, right to self-determination, privacy, and confidentiality of personal information" ¹⁶⁵ p. 2</sup>. The declaration was developed to guide physicians through research on patients and encourage all others involved in research on humans to apply the principles as every researcher is responsible for holding the appropriate education, training and qualifications in ethics and science¹⁶⁵. Throughout the research process of this thesis, considerations have been made, and steps have been taken, to ensure that the meaning of the declaration has been fulfilled.

Risks, burdens, benefits in vulnerable groups and individuals

Most research interventions involve risks and burdens and should be carried out only when possible profit outweighs the risks which apply to the principles of beneficence and non-maleficence¹⁶⁶. This is especially important when research is performed on vulnerable research persons¹⁶⁵, such as ill children. As this thesis includes observational studies, study participation is not likely to put research persons at physical risk, although participation still implies certain burdens. In a strained period of time, families dedicate time and effort to contribute to improved knowledge, which should not be taken lightly. At the same time, for the sake of justice¹⁶⁶ optimal research should be conducted on behalf of underrepresented groups¹⁶⁵ such as children. Only children themselves can contribute a child's perspective⁷⁶ and their participation is thus needed. Their right to participate is further stated in *UN Convention on the Rights of the Child*¹⁵ and in Swedish legislation⁷⁰. Both children and their parents have further shown interest in child participation in research¹⁶⁷. To decrease the burden of study participation, families were given the opportunity to choose the time and place for interview and children were encouraged to participate only for as long as they wanted

to. All families were further informed that they had a possibility to contact a named counsellor at the hospital or HCS if in need of counselling.

Scientific requirements and research protocols

The present thesis, in accordance with the declaration¹⁶⁵, was based on available scientific knowledge. It was further guided by a study-protocol developed in the early stages of the research process¹⁶⁸, also containing ethical considerations, funding and sponsor information, institutional affiliations and incentives for participation¹⁶⁵.

Research ethics approval and research registration

Prior to recruitment of study persons, the studies were approved by the independent *Regional Ethical Review Board* (Ref. No. 2014/818) and by the *Institutional Review Board* at Skåne University Hospital (181-17). Heads of HCS units and paediatric departments in Region Skåne further gave permission for recruitment. When parts of the research plan underwent revision¹⁶⁸, the ethical implications were considered and at one time a renewed approval was obtained¹⁶⁵ as inclusion criteria were extended to include more participants. In 2015, when the studies opened, there was no need for registration of non-interventional studies in Sweden.

Privacy and confidentiality

Several precautions have been taken to protect the privacy and confidentiality of the research persons¹⁶⁵. Thorough information about the design of a focus group interview was given to ensure that presumptive participants were comfortable with the required sharing experiences in the presence of other colleagues. All research persons were offered to choose an interview with team members from their own unit or with participants from other units. Recruitment of ill children and their families was performed in two steps with the possibility to respond to invitation for participation either to the HCS contact person or directly to the research group. After the initial contact, no information was shared between the research group and the HCS contact person.

When research concerns a small population such as sick children receiving HCS, there is always a challenge to uphold confidentiality, and extra efforts were taken to minimize the risk of children being identified in the final publications. The optimal number of reminders to families who did not return questionnaires has been reflected upon. Repeated reminders have been found effective for increased response rate and at the same time it may violate the family's privacy to be too persistent in seeking for replies¹⁶⁹. The chosen path, to only send one reminder, was thus taken in respect for the family's privacy at the potential expense of validity of data. All questionnaire data were coded

according to Swedish legislation and *The General Data Protection Regulation*¹⁷⁰. A code-key, stored separately from the data, was obtained and all research data, including transcription and electronic records of interviews, were encrypted to ensure confidentiality and are protected against access from unauthorized persons.

Informed consent and assent

All research involving humans should be voluntary and the right to refuse participation or to withdraw consent at any time without reprisal should be clarified¹⁶⁵. Thus participation was preceded, whenever possible, with collection of written informed consent for aim, methods, sources of funding, researcher affiliations, potential risks and discomfort, methods for data storage and use of findings¹⁶⁵ from healthcare providers and family members and children aged 15–17. The autonomy¹⁶⁶ of young or severely ill children must be given special attention. Caution must be taken when children are not able to consent and research only carried out if it cannot instead be performed with persons capable of providing informed consent¹⁶⁵. Age-adjusted written information was mailed in advance of the interview. Individualized oral information was then given before each interview, emphasizing that participation was voluntary and clarifying the right to discontinue or participate intermittently in the interview¹⁷¹, of one's own accord and without consequences,. All participating children under the age of 15 gave in one way or another assent either orally or in writing.

Publication and dissemination of findings

The main findings from this thesis have been presented at scientific meetings and in peer-reviewed journals. This thesis further helps disseminate findings and experiences gained during the research process, in line with the *Declaration of Helsinki*. As the studies have clinical implications, efforts have been made to disseminate findings also in the community and in particular in healthcare services through educational sessions and presentations, newspapers, websites and social media. Presentations and publications have included a declaration of ethical approval, funding, institutional affiliations and conflicts of interest to ensure transparency¹⁶⁵.

Findings

Home care service for sick children

The findings section present the results merged in congruence with convergent mixed methods. The first section of the findings serves as an orientation by describing *Accessibility, utilization and healthcare costs* of the HCS. The following sections are structured in order to highlight its relationship with the theoretical framework chosen for this thesis. Three main interacting areas were identified: *Relationship-building through time and cooperation; Demand for sustainability in everyday family life and health,* and *Anxiety, trust and feelings of safety.* Findings are described with reference in parentheses to the paper in which the findings are presented (I–IV) or to this thesis if not included in papers I–IV (thesis).

Accessibility, utilization and healthcare costs

The 203 children referred to HCS, as well as the 171 receiving HCS, had a broad range of illnesses and care needs (III) with diverse associated healthcare costs (IV). Children in all ages (mean 5.5 years) and resident in different places in the county received HCS with significant differences in allocation of referrals of children with certain diagnoses and indication for palliative care to different HCS units (III). The children's families differed in several ways in relation to, for example, number of siblings (0-4), parental education and level of work absenteeism (0-100%) (IV). Parents stated general healthcare satisfaction, 86 out of 100 possible in the initial month of HCS and slightly lower, 82, later in the follow-up period (Table 4) (Thesis). Annual HCS costs for care when provided by both hospital and HCS were on average SEK 50,101 per child lower than for care only at the hospital (IV). Eighty-nine (89) percent of the total number of 355 referrals were accepted for HCS while eleven (11) percent of the referrals were rejected with reference to different reasons such as lack of resources in HCS or because HCS was not a suitable service to perform the requested task (III). In total six (6) percent of the referrals concerned palliative care (III) while children receiving palliative care composed 74% of the total HCS costs (IV). Caring for these children was experienced as particularly demanding although simultaneously especially personally meaningful (I).

Paper mean (SD)	Mothers N=20 T1	Mothers N=25 T2–5	Fathers N=17 T1	Fathers N= 21 T2–5
Healthcare satisfaction	84.5 (11.8)	82.9 (14.2)	87.0 (12.4)	81.1 (19.2)
Trait	37.3 (7.7)	_	36.4 (8.9)	-
State	36.2 (14.0)	36.0 (13.0)	39.4 (13.6)	36.3 (13.1)

Table 4. Parental healthcare satisfaction and anxiety. N = number of measures

Relationship-building through time and cooperation

The relation between families and HCS healthcare professionals was experienced by both families (II) and HCS healthcare professionals (I) as being of great importance. Parents showed overall preference for HCS rather than hospital care in 209 out of 212 days of HCS visits (III). At the same time relationships were experienced as taking time to build (I, II). One family stated by questionnaire (III) that after their first visit they would prefer not to have HCS in the future but continued and stated after one week of HCS that they would absolutely chose HCS again if possible (Thesis). One mother expressed it thus:

"The first day [the child] was a bit puzzled. I believe she wondered, what are they doing here with the white clothes that belong to the hospital? But then, we made up routines and when they came here she went to the bed! So they arrive and start to prepare and she goes to prepare herself!" (Mother) (II)

The relationship that was built up was conceived as fragile and easy to lose (I). The possibility to get to know each other during a calm period of illness helped HCS healthcare professionals to understand the family's needs and give optimal customized care during more difficult periods of illness such as at the end of life (I, II). Straight and understandable communication supported family members' shared decision-making in planning and delivering the HCS (II).

HCS healthcare professionals experienced that even if they were used to working alone in the home of a family with children it felt different when the child was the patient instead of a close relative. Most often HCS visits (95%) were performed by HCS nurses (III). A majority of these were SCT (III), where nurses performed tasks without the supporting multi-professional collaboration, which sometimes led to professional challenges. Nurses conceived it as important to adjust prerequisites according to the children's and families' needs, for example by visiting the family in pairs with a colleague (I). When the HCS healthcare professionals used the available conditions in terms of time and knowledge to care for the child in his or her safe environment, they were experienced as providing individualized care, based on the child's needs, in a way that would not have been possible for healthcare professionals at the hospital (II). HCS was also experienced as a way of getting both the ill child and the sibling more involved in the care.

"When he has friends over and I have friends over during a homecare visit he always wants us to be there and watch" (Sibling) "There!" (Sick child smiling and pointing at the sofa) (II)

Well-established cooperation between family, HCS and the referring paediatric department contributed to feelings of stability with the possibility for a "second opinion" for the family (II) and a source of collegial support and knowledge for HCS healthcare professionals (I) and was thus important. When attempts to bridge the gap between HCS and the paediatric department failed, both families (II) and HCS healthcare professionals (I) felt abandoned.

Children were referred to one of the eight HCS units in the county by a physician within any one of the paediatric departments at the university hospital or local hospitals in the county (III). HCS healthcare professionals experienced children as a small and yet complex group of patients and as such also a demanding group of patients to become familiar with (I). Throughout the three-year study period there was no sign of increased referrals or utilization of HCS (III), although HCS healthcare professionals felt that, if the number of children were to increase, they would grow more familiar with this group of patients and through time feel less insecure (I).

Demand for sustainability in everyday family life and health

Long-term or chronic in a child sometimes had an impact on everyday family life, such as parents' work hours and children's school attendance, also when part of the care was given in the home (II, IV). Even so, HCS was experienced as strengthening everyday family life for the whole family for many reasons. Children were able to meet friends or be with their pets. Care in the home for the ill child interfered less with the siblings' everyday life and parents did not have to spend time preparing for hospital visits (II). Occasionally, parents stated that siblings were able to sleep at home instead of with a friend (thesis) and siblings felt relieved as they knew someone in the family would be at home (II).

Twenty-five (25) parents of 14 children reported an annual mean reduction in work of 347 hours (SD 465) per parent. There was a trend towards more extended reduction in hours by mothers than fathers, while the value of productivity losses showed the opposite trend (IV). Four parents with long-term illness in their child, adjusted their

estimation of the time they would have worked, especially towards less working time, if the child had not been ill throughout the year of observation (IV). Still parents expressed increased possibility for work as a positive effect of HCS (II).

The feeling of sustained or retained stability in everyday family life offered families some relief and enabled family members to reflect on their situation and also reach out for psycho-social support in a way that had sometimes been difficult during hospital care (I, II). This was experienced as strengthening health for both parents and children including siblings who were given much appreciated attention (II).

"When they came here, they offered the two of us (looking at the mother) to do something together!" (Sibling) (II)

HCS healthcare professionals tried to adjust care according to the families' needs in order to offer families the choice of being at home (I, II) and, especially during palliative care, families experienced how HCS healthcare professionals made efforts to serve their needs, for example by being flexible about time (II).

Anxiety, trust and feelings of safety

Mean parental anxiety levels were moderate throughout the follow-up period, with more pronounced deviations for State-A than Trait-A (Table 4) (Thesis). When parents felt that the relation with HCS healthcare professionals was trustful, it helped them relax (II) and, in turn, when parents appeared to be calm this helped the HCS healthcare professionals to be calm and act professionally (I). Twenty-three parents stated their own feeling of safety as high or very high in 97%, and their child's feeling of safety in 79%, of 212 days of HCS visits (III).

When trust was not achieved and families felt abandoned or alone with their concern for the child's well-being. Both parents and children experienced high levels of anxiety and described feelings of despair (II).

"You feel alone, and insecure. Oh, your child is ill and will not survive it and they [home-care professionals] ask that type of questions. Then you get really mad." (Mother) (II).

HCS healthcare professionals felt mixed personal and professional emotions about providing HCS for sick children (I). Both the diagnosis of cancer, accounting for 30% of the referred children, and administration of intravenous antibiotics, constituting the reason for referral in 57% of the referrals (III), were well known from the adult group of patients, as was provision of end-of-life care (I). Ten percent of the children who received HCS died during the three-year period, a majority of whom were referred to palliative care (III). At the same time it was conceived as more demanding to care for a

child with severe illness than for an adult and it was both professionally and personally demanding to cause a child pain, for example during administration of a drug (I). To alleviate some of the demands, HCS healthcare professionals used the supportive organization already in place within the HCS organization, for example well-established multi-professional teamwork and scheduled debriefing (I). While both families (II) and HCS healthcare professionals (I) experienced positive effects of HCS for the families, HCS healthcare professionals struggled to understand why care for sick children was added to their task assignment (I). Sometimes overwhelming feelings were easier to contain when reasons were communicated to them in an inclusive and understandable way by the HCS management (I) and they were encouraged to put an effort into the work (I).

Discussion

Methodological considerations

Perspectives of parents, ill children, siblings and healthcare professionals as well as documented data of healthcare service and administrative documents have contributed to a multifaceted picture of HCS for children. A convergent mixed methods design¹⁴¹ with data from interviews, psychometric instruments, customized questionnaires, medical records and administrative systems was used to provide a comprehensive view of HCS for children provided by county-based HCS. There is a risk that, when seeking for comprehensiveness, you grasp too much and only discover the surface and that scientific rigour is lost. Therefore, methodological steps have been undertaken throughout the study-process to enhance the quality of data collection, analysis and interpretation of findings¹⁶⁸.

Scientific rigour

Rigour in sciences refers to the accuracy of the chosen design and the strategies chosen to verify the research process according to the research question. Verification strategies help the researcher identify when to make adjustments in the research plan in order to achieve rigour¹⁶⁸. Traditionally rigour in quantitative research has been verified by validity and reliability measures, while researchers during the 1980s developed a separate set of measurements for assessment of qualitative research¹⁷². Trustworthiness including credibility, dependability, confirmability and transferability has been the golden standard concept for researchers to reflect on scientific rigour in qualitative research. However, strategies to verify trustworthiness can be considered to evaluate rigour rather than in themselves, to ensure rigour. They involve actions taken at the end of the research process rather than before and during the process. This leads to a risk of missing threats to the validity and reliability of the studies until it is too late to correct them. The two paradigms of research are thus measured with different scales, which becomes visible in, and brings challenges to the verification of, mixed methods studies forming the third, pragmatic, paradigm¹⁶⁸. Morse argues that the terms validity and reliability are used for assessment in both quantitative and qualitative research¹⁶⁸, which will be applied here.

Internal validity

Internal validity refers to the validity of the conclusions drawn from the research¹⁴⁶. Morse states that it is essential that the investigator remains open, uses his or her sensitivity, creativity and insight, and is willing to abandon any ideas that are poorly supported no matter how promising they might have seemed¹⁶⁸. Throughout the research process, design and issues such as inclusion rate, have been discussed within the research group and earlier versions of the plan have been revised to obtain high internal validity.

Each method carries its own weaknesses and strengths. Studies using one single method thus carry a higher risk of validity weaknesses due to methodological errors than a multi-method approach¹⁷³ such as a convergent mixed method design¹⁴¹. Whereas the sample in a qualitative study might not be large enough to show statistical differences, it provides deepened understanding and critical information about subgroups and variations that would have been overlooked with quantitative measures. Information on these subgroups, for example those situations where HCS did not meet families or healthcare professionals' needs, are vital to identify and reflect on¹⁷³ in order to organize and provide high-quality HCS for children based on family members and healthcare professionals' needs.

A purposeful sample selection congruent with the study aims was used to gather rich and varied data¹⁷³ through interviews with healthcare professionals and families. Participants both contradicted, continued and deepened each other's conceptions. The internal validity of focus group interviews is threatened by the risk of culturally inappropriate or sensitive areas being left out. Healthcare professionals of various ages were included, with different professions and different amount of experience of countybased HCS and from providing care for children. The chosen method for selection also increases the risk of not involving individuals with all possible conceptions. The fact that nurses account for the majority of the participants in this study could both strengthen and lower the internal validity. Nurses performed the majority of the HCS visits and as such their experiences are important when describing conceptions of providing HCS. However, their numeric majority in focus groups might also have given potential nurse-specific conceptions an advantage during data collection. When conducting research on matters that concern children, research is strengthened by including the child's own perspective as a complement to a child perspective that can be subsidized by others⁷⁶. In this thesis efforts were made to grasp a child's perspective by involving children in interviews⁷⁶, although it would have been desirable to give their voice an even more central role. Kirk¹⁷¹ identifies two methodological issues when conducting research that includes children. One is the issue of heterogeneity within the group and the second is the different cultures of childhood versus adulthood, which forces the researcher to consider methodological issues and be prepared to use innovative techniques in research¹⁷¹. Pictures and photographs have proven to be a useful way to enhance children's memory^{150, 151} and supply information sharing by

individuals at the end of life¹⁷⁴ by helping them express their experiences. However, in the present study this method was not a successful way to increase the richness of the data. Instead, other efforts were made to make the children active participants throughout the interviews. As children contributed in various ways during interviews in a manner that broadened the experience, the interviews were carried out with no further adjustments from the study plan¹⁶⁸. Several additional ways could possibly have facilitated children's participation in data collection, and thus enhanced internal validity, all bringing their own benefits and drawbacks¹⁷¹. For example, making observations during HCS visits or letting the child become familiar with the interview situation¹⁷¹ by a series of shorter interviews rather than a few longer ones could have further strengthened internal validity.

The response rate to follow-up questionnaires was relatively low, which further lowers the internal validity and required adjustments to outcome measures. Several questionnaires and forms developed by the research group were used in the studies and contained both strengths and weaknesses. The same questionnaires and forms were used for all participants and throughout the study period, which strengthens internal validity as it allows comparison. However, some of the questions were shown to be imprecise, for example data on relatives' absenteeism from work, and therefore difficult to use for quantitative analysis. This limits the possibility to draw conclusions on productivity losses from a societal perspective.

External validity

External validity refers to the adequacy of generalization from the research findings to other contexts such as other groups of individuals, other times or geographical places¹⁴⁶. Due to the inclusion processes in this thesis, the sample selection might hold different biases, which limits the potential for generalizing the findings. Contact information from 50 (28%) of the families with a child receiving HCS during the three-year period was handed to the research group and 36 (21%) of the families eventually participated in one or more data collection. The number or families who agreed to participate but did not provide any data at all or omitted to provide data for all follow-up time-points was rather large. The reasons for this are not known, but might be related to the relatively slow inclusion process and long-term follow-up in relation to the median duration of HCS at 7 days. To optimize the response rate, all families who did not respond received one reminder by e-mail or telephone and also received the forms and questionnaires in time for the following two observation periods.

Questionnaire-based data were gathered from a limited, uncontrolled sample, which lowers the possibility for generalization. However, the external validity of each separate study is strengthened by the mixed methods design as findings from several data collections confirm, complement or support each other¹⁴¹.

Non-Swedish-speaking families are a growing population in Sweden, with about 17% of the population born outside the country⁹⁷. Even though the sample in this thesis includes single children and several parents born outside Sweden, it is thus a limitation to have included only those who speak Swedish¹⁶⁵. Possibly, as communication has been found crucial for trustful HCS, this group should not only be included but highlighted in future studies in order to expand the potential for generalization of the findings.

The HCS constituted a new and complex service with a large number of staff and services around the clock. Study contact persons as well as heads of HCS were regularly supplied with reminders and encouragement and efforts were made to disseminate information about the studies to all HCS health professionals. With no knowledge of the suspected flow of eligible children it was difficult to supervise to what extent families were given information and when to intervene. There was positive communication about the ongoing research at all HCS units although gatekeeping among palliative care healthcare professionals has previously been identified as a challenge for introducing a family to research^{175, 176}. Thus, more extensive supervision by the research group might have increased the number of families included and thereby increased external validity.

Reliability

Reliability refers to the accuracy and consistency of measurements¹⁴⁶. To strengthen reliability, two psychometrically instruments (STAI-Y and PedsQL healthcare satisfaction), widely used in research with parents of sick children and validated with factor analysis and internal consistency were used. The reliability of the acceptability questionnaire was tested and found feasible to use in a previous HCS study¹¹ and in this study. However, the questionnaire could, possibly be optimized by adjusting items towards a Likert scale approach with a neutral mid-point and items designed as statements possible to agree or disagree with¹⁷⁷.

Missing data, for example for absenteeism from work, made it necessary to perform health-economic analyses based partly on estimations. The reliability of these estimations is strengthened by information on concepts and sources for assessing healthcare costs and productivity losses, which allows readers to make their own alternative calculations¹⁰¹.

Focus group interviews were chosen in favour of individual interviews for data collection as group interaction may have potential synergy effects on participants in a focus group and stimulate experiences and views leading to deeper and broader data¹⁴⁹. During focus group interviews, one potential threat to reliability is the difficulty of keeping the focus on the aim of the study¹⁴⁹ especially for a single and unexperienced researcher. This threat was minimized by the presence of a second researcher, more experienced in interview methodology, participating as an assessor. During the family interviews the option of two participating researchers was deselected due to family privacy and the risk of taking too much focus from the families' own narratives. For

both interview studies, interviews were recorded and transcribed verbatim together with notes on body language and other communication from interview participants to minimize bias due to preunderstanding, memory loss or involuntary interpretation. A naive reading of all the transcribed interviews was performed independently by all co-authors¹⁷³. To ensure rigour, discussions on similarities and differences in understanding of data took place among co-authors throughout the analysis process. During discussions, the authors moved back and forth between parts and the whole following the hermeneutic spiral¹⁴⁵ to make sure that the nature of the phenomena in focus is truthfully reflected¹⁷³.

General discussions of the findings

In this thesis findings from various data-collection methods have contributed to a deeper and broader knowledge of county-based home care service for sick children. When merging findings based on widely different types of data, there are challenges in terms of measures for comparison. In this thesis, they have been given equal meaning without internal ranking¹⁴¹. The main findings were that county-based HCS can be provided to children of all ages and with a variety of illnesses and healthcare needs in different stages of illness, without increased healthcare costs and with decreased number of days spent at the hospital. HCS provision built on trustful alliances between the family, HCS healthcare professional and the paediatric department can strengthen everyday family life and health. Furthermore, caring for a child can be professionally and personally challenging and can simultaneously support HCS healthcare professionals towards personal and professional growth. The findings will be further discussed in relation to the theoretical framework in the thesis.

Home care service for sick children and its relation to Bowen family systems theory

Qualitative data in the thesis show how families felt that HCS strengthened everyday family life by providing better conditions for living a normal life compared to care at the hospital while quantitative findings showed vague objective changes in everyday life like school- or work attendance. The same pattern has been identified earlier. For example, interview-driven studies^{113, 115, 117} found profound positive experiences while questionnaire-based studies found no or little^{11, 178} impact on quality of life. This can be explained by the fact that less effort is required to maintain what is well-known and balanced²⁰ rather than a real change. The threat that something may affect everyday family life leads to increased tension in the family²⁰ and with HCS this tension may be decreased and families feel relieved.

At times, levels of anxiety was experienced as high by parents while receiving HCS whereas levels of anxiety as measured by STAI-Y were quite moderate for both mothers and fathers throughout the period of care. Stevens et al. (2006) found that HCS provided by HCS healthcare professionals not experienced in paediatric care might induce parental stress¹²¹. A study on mothers of children with various diagnoses receiving enteral nutrition at home without the support of HCS showed much higher levels namely 88 (State-A) and 49 (Trait-A) respectively^{52.} This indicates that mothers found themselves in a particularely stressful situation during HCS. Our findings of high feeelings of safety and overall moderat levels of anxiety in this selected population of parents offered and willing to accept HCS as an alternative to hospital care can be explaned in different ways. First, aaccording to Bowen's family systems theory, changed levels of tension affects the triangular relationships between family members in the immediate family as well as with relatives and health professionals. Depending on how the relationships are founded and formed, they can then be strengthened or reduced when the tension is changed²⁰. Second, the step from in-patient care at the hospital to being in the home with the ill child has been shown in other studies to be emotionally demanding for families. The transfer should be planned and supported accordingly^{120,} 122, 179, 180, emphasizing possibilities for communication with healthcare services¹⁸¹ in order to restrict levels of tension. The predictability of future care and the possibility to become familiar with a new care service in a calm period of illness was also experienced as important by parents, as seen previously9. This is furthermore in line with the integrative palliative care approach, emphasizing the possibility for HCS throughout the trajectory of illness⁸⁰ and giving families time to build on strong relations with healthcare professionals. When applied only to the far end of life, findings in this thesis suggest that there might not be enough time to build trustful alliances holding for potential periods of increased tension¹³⁴, for example when the child is in pain or during the time of death.

One HCS healthcare professional conception was that the child would feel safer getting treatment in the hospital than in the home. Family members in the thesis also reflected on individual frontiers for when they would no longer feel safe with care at home without increased levels of anxiety and possibly increased tension in the family relations¹³⁵. For example, blood sampling could both be the reason for choosing HCS and a reason for choosing the hospital. In a study by Aasen et al.¹¹³ parents found it better when competent nurses performed painful procedures in the home environment where the child felt safe rather than in the hospital. Thus, varying choices may be driven by family members' ways of dealing with potential stressful events, which in turn is based on prior experiences and actions from other family members²⁰. With instable relations and negative experiences of tension, distress in a child may contribute to overwhelming feelings of anxiety in a parent and further into feelings of insecurity among HCS healthcare professionals. In another situation the tension is experienced as manageable and feelings of safety were retained²⁰ also during painful procedures at

home. Not only parents and children in the nuclear family²⁰ are affected by HCS. Grandparents were able to be present and near at hand, which can entail comfort and further decrease tension in the family also during strained periods of illness. However, HCS for families with distant or fragile relations with relatives outside the immediate family might, according the Bowen family systems theory, instead lead to increased feelings of loneliness¹³⁴. The emotions could eventually be sedimented within and among family members so that future periods of HCS or situations inducing similar emotions might have effects both on the nuclear family and on coming generations¹³⁴.

In accordance with Bowen family systems theory¹³⁴, HCS healthcare professionals in this thesis found relief in families' trust and well-being, which made the healthcare professionals calm and able to perform professionally. Family members describe how HCS healthcare professionals were experienced as focusing on the child in a way that healthcare professionals in the paediatric hospital had not. This shows how active participation by the child can be increased through HCS, as also shown in previous studies^{12, 122}, and that child-centred care⁷⁴ can be provided by county-based HCS. Enough time for each home visit, the opportunity to adjust care and good communication with families were perceived as important to create a trusting relationship that can also hold for tension, as also described by Samuelson et al.¹²⁴ and Chong et al.¹²⁵

While highlighting the possibilities for strengthened everyday family life and health for families with ill children receiving home care, this thesis also identifies situations where inadequate communication and lost trust made HCS less successful. Previous studies have identified ways of strengthening communication between the hospital and the family, for example by the use of tele-¹⁸² or video-^{183, 184} communications, which might lead to stronger relationships also during periods of HCS.

Home care service for sick children and its relation to the Demand for health theory

HCS healthcare professionals experienced that they used more resources while providing care for children than when providing care for adults. As also shown in a previous study¹²⁴, they adjusted their professional achievements both according to family's needs for sustainability in everyday life and according to their own needs due to the strained task of caring for a sick child. For example, they spoke about making home visits in pairs, spending time becoming familiar with the child, having extended collaboration with the referring hospital and consuming extra time for debriefing. These investments of resources optimize families', as well as their own health capital¹³⁷. This thesis found no increase in estimated healthcare costs which can be added to the list of reasons for increasing accessibility and utilization of county-based HCS for

children. However other, more detailed, methods for calculating costs related to the actual use of staff recourses could possibly have influenced the findings.

Study 3 show a continued extensive work absenteeism throughout periods of HCS for the ill child. The design of the study does not allow us to draw conclusions on the extent to which the place of care or the illness itself contributed to this absenteeism. However, in interviews parents described the possibility of decreased use of temporary parental benefits with HCS instead of care in the hospital. Occasionally, parents adjusted their estimates of their planned working time if the child had not been sick so that estimated working time were either higher or lower due to illness. Wakefield et al. describe parents' choice to prioritize time with the family higher after treatment from childhood cancer than before¹⁸⁵. Previous studies have shown mixed correlations between long-term childhood illness, such as cancer, and parental career. For example, employment was effected in different ways during treatment¹⁸⁶ and both employment¹⁸⁷, salary¹⁸⁸ and longterm sick leave¹⁶⁴ have been found effected negatively after the end of treatment. Thus, parents make individual¹³⁷ and family unit¹³⁸ healthdemand-related choices in order to maintain optimal health within the family in a lifetime perspective^{137, 138} and HCS can possibly help families optimize the level of work according to their unique, present and future, needs.

Furthermore, we found a trend of clinically relevant higher level of productivity losses among mothers than among fathers, while the value of the productivity losses was almost evenly distributed or even reversed. This is in line with previous studies reporting gender differences in productivity losses related to childhood illness¹²⁸. The study¹²⁸ showed that when the distribution changes during HCS so that fathers take a higher percentage of parental leave, the families' economy can be negatively affected. Thus this investment makes sense only if the parents view it as a perceived gain of the family's health capital¹³⁸.

Occasionally, children with long-term illness were found to increase their school attendance during the follow-up period. Family members expressed how HCS increased possibilities for various forms of interaction with friends and teachers in the school which is in line with previous studies^{46, 113, 115}. Siblings could rely on the family being at home, less time and energy was spent on worries and planning for everyday life. This might lead to savings of the health capital of the ill child, siblings²¹ and of the family as a unit¹³⁸.

Final remarks

One challenge for healthcare services directed to small groups is the balance between accessibility and utilization. When the number of children is limited and care needs are divers as often in county-based HCS, this thesis confirms that a population-based generic service might optimize time accessibility⁹⁴. Further studies on actual costs rather

than costs based on cost-lists would strengthen the scientific base for healthcare costs associated with HCS. However, a full health-economic evaluation of cost effectiveness or cost utility might be difficult without a randomized design, which in turn might not be recommendable from an ethical point of view.

HCS for children in the county of Skåne started in 2014 as a political response to the demand for increased availability of HCS for children. Ideally, implementation of new models of healthcare are supposed to build on a scientific base and a structured process is recommended to increase the quality of implementation¹⁸⁹. The Medical Research Council (MRC) suggests a process including development of a theoretic base, piloting an intervention, evaluation of intervention and implementation of intervention when processing complex interventions in healthcare¹⁸⁹. Still new models or organizations for delivering care are constantly evolving and put into clinical practice with varying scientific support. Changes in health-care organization, political decisions or economic aspects may drive the introduction of a new model of care just as well as scientific evidence. When this is the case, as in the present setting, the MRC shows how research has an important role in evaluating implementation while building on the theoretical base¹⁸⁹. However an implementation strategy could possibly have increased the total number of children receiving county-based HCS and moreover reduced unequal accessibility and utilization.

Conclusions and clinical implications

With trustful alliances between families, HCS and paediatric departments, costsustainable county-based HCS can be provided with high levels of family acceptability and positive effects on family life and health for sick children in various ages, with different illnesses and stages of illness. However, unequal accessibility and utilization jeopardizes care based on child and family needs, and challenges related to the need for successful communication and individualized care must be met.

HCS was found to support parental participation in care, in accordance with previous research¹²². HCS healthcare professionals had limited training and expertise in paediatric care although they had the ability to provide care based on children's and families' needs as experienced by parents. Competences in, for example, palliative care and experiences of professional care for an individual in their home thus seem important. Furthermore, viewing the child in their own home and allowing siblings and ill children to participate on their own terms enables HCS to provide care in accordance with child-centred care⁷⁴.

High-quality HCS requires cooperation among families and healthcare professionals at the HCS and paediatric departments.

Referral to and utilization of HCS was low and unequally distributed in the county, which might be due to several different reasons. Regardless, this thesis shows that the implementation of a new healthcare service such as county-based HCS for sick children might be unequally distributed and thus directed efforts may be needed to increase and even out these inequities.

Further research

The findings in this thesis may serve as a foundation for designing larger studies on correlations and causation between HCS utilization, diagnoses, healthcare costs, productivity losses, school attendance, use of parental benefits, levels of anxiety and healthcare satisfaction among families receiving HCS. Such studies would provide more detailed knowledge on HCS for sick children.

Implementation of a new healthcare service is known to take time and might need support by structured clinical interventions. A follow-up study on accessibility and utilization in the same setting within a couple of years can contibute further knowledge from an implementation perspective.

Increased understanding, for example by means of a survey or qualitative study focusing on paediatric department healthcare professionals' attitudes, norms and knowledge regarding HCS, would be valuable for future interventions aiming at increasing the accessibility of HCS for sick children.

The transfer between hospital and home and the initial period of HCS contain special challenges and further knowledge of how the risk of feeling overwhelmed by responsibility might be relieved, for example by e-health, would be beneficial for clinical implementation.

In future research on HCS for children, efforts should be made to include non-native families as they may have specific needs during HCS and as communication failures might bring additional challenges for this group of families.

Svensk sammanfattning

Sjukhusvistelser hos ett barn kan påverka hela familjen psykosocialt och praktiskt och många familjer föredrar vård i hemmet framför vård på sjukhus. Samtidigt varierar modeller för organisation, finansiering och genomförande av sjukvård i hemmet nationellt och internationellt och det kan vara svårt att överföra kunskap mellan länder och organisationer. Kunskapen om vad som är viktigt för att ge vård i hemmet, av olika modeller, med hög kvalitet, till barn, är begränsad och mer forskning behövs. I Sverige varierar tillgången till vård i hemmet för sjuka barn mellan olika delar av landet och den vård som erbjuds är oftast organiserad av landstinget antingen i form av sjukhusanknuten hemsjukvård eller avancerad sjukvård i hemmet (ASIH). Det övergripande syftet med denna avhandling var att utifrån olika perspektiv undersöka ASIH för barn, utförd av en verksamhet organiserad för att ge ASIH till både vuxna och barn. Resultat från kvalitativa och kvantitativa studier sammanfördes för att ge en djup och bred bild av vård i hemmet till barn med olika sjukdomar och i olika faser av sjukdom.

Denna avhandling genomfördes i Skåne under åren 2015–2019 där möjlighet till ASIH för sjuka barn tidigare varit mycket begränsad. 2013 togs ett politiskt beslut att ASIH skulle erbjudas alla invånare i behov av vård i hemmet oavsett diagnos, prognos eller ålder. Verksamheten är organiserad i åtta enheter och kan under hela dygnet ersätta komplexa hälso- och sjukvårdsinsatser på vårdavdelning, dagvårdsenhet eller mottagning. Insatser ges antingen som punktinsats där exempelvis en sjuksköterska från ASIH ger antibiotika i hemmet efter ordination från läkare i barnsjukvården, eller som palliativ vård där ett multiprofessionellt ASIH-team övertar ansvaret för barnets vård.

Med hjälp av fenomenografisk metod genomfördes och analyserades fokusgruppintervjuer med 37 professionella vårdgivare. Att vårda barn uppfattades som en personlig och professionell utmaning men också som givande och meningsfullt. Möjlighet att påverka sin arbetssituation, tillräckligt med tid och resurser för att skapa tillit hos familjen och samarbete med barnkliniken uppfattades som viktigt för att ge ASIH på ett tillfredsställande sätt. Den levda erfarenheter av ASIH när ett barn är sjukt undersöktes med hermeneutisk fenomenologisk metod. Totalt 12 familjer, varav 4 sjuka barn, 10 syskon och 23 vårdnadsgivare (föräldrar) deltog i 15 intervjuer. Att få vård i hemmet kunde ge förutsättningar för att familjens tid och resurser sparades så att vardagsliv och hälsa kunde stärkas. God kommunikation och tillitsfull relation med vårdgivare i ASIH och ett fungerande samarbete med barnsjukvården under perioden av vård i hemmet var viktigt för att familjen skulle känna trygghet. En granskning av alla remisser till ASIH på barn under en treårsperiod visade att 171 barn i åldrarna tre veckor till 18 år, med vitt skilda diagnoser och vårdbehov, fick ASIH. Hälften av barnen var under skolålder, 57 % av remisserna gällde intravenös administration av antibiotika och 6 % av remisserna gällde palliativ vård. Vanligaste diagnoserna hos barnen var onkologisk sjukdom (25 %) och neuro-borrelios (17 %). Det fanns skillnader inom regionen rörande hur stor andel av remisserna som gällde intravenös antibiotika och palliativ vård samt hur stor andel remitterade barn som accepterades för vård. En subgrupp av svensktalande föräldrar, boende i Skåne och med barn som fick ASIH, inbjöds att delta i en studie om hälso- och sjukvårdskostnader samt familjens vardagsliv och föräldrar till 36 barn lämnade skriftligt medgivande om deltagande. Uppgifter om vårdkonsumtion från administrativa system och regionala prislistor insamlades med hjälp av en strukturerad mall. Kostnaderna för ASIH visade sig stå för en liten den av den totala hälso- och sjukvårds-kostnaden och kostnad för hälso- och sjukvården ökade inte när ASIH gavs som en del av total vård jämfört med vård utförd bara på sjukhus. Demografiska familjeuppgifter inhämtades via frågeformulär från föräldrar. Föräldrar skattade höga nivåer av sin egen, och sitt barns, nöjdhet och trygghet efter ASIH besök, och uppgav önskan om fortsatt vård i hemmet vid 209 av 212 besök. Tjugofem föräldrar uppgav tjänstetid, orsak till frånvaro från planerat arbete samt lön vid fem tillfällen under ett år. Analys av samhällskostnader i form av föräldrars frånvaro från arbete på grund av vård av barn varierade mellan 0 och 100 % och var omfattande i början av observationsåret även då barn fick ASIH.

Resultatet från studierna relaterades till Bowens familjesystemteori och Grossmans hälsoekonomiska teori som förtydligar hur familjemedlemmar samverkar med andra närstående i ett interaktivt system och gör olika investeringar för att nå optimal hälsa. Vidare sker såväl, inom familjen som mellan familj och omvärld, ständiga förskjutningar och påfrestningar av relationer som påverkar upplevelsen av en situation som ASIH både i nutid och över generationer. Därför måste varje barn, familj och personal hanteras individuellt och varje situation kunna anpassas.

Sammanfattningsvis visar avhandlingen att ASIH kan ges till barn i alla åldrar med en mängd olika sjukdomstillstånd vid olika stadier av akut, långvarig eller kronisk sjukdom och med hälso- och sjukvårdskostnader som inte överskrider vård som ges enbart på sjukhus. Vård kan ges med hög tillfredsställelse hos barn och föräldrar men fungerande kommunikation och samarbete mellan familj, ASIH och barnsjukvård är viktig för att familjer och personal skall känna förtroende och trygghet med vård i hemmet vid sjukdom hos ett barn. Resultatet ger vägledning för framtida organisation och implementering av ASIH för barn.

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Appendix

Introduktion

Start

Vi är intresserade av *hur ni ser på* att ge vård i hemmet till sjuka barn. Hur ni uppfattar det. Vilka hinder och möjligheter som kanske finns och vad som är viktigt för er, för barnen, familjerna... det finns inget rätt eller fel svar. Det vi vill höra om är era uppfattningar. Vill ni börja med att berätta om hur ni känner just nu i förhållande till att vårda barn

Probing-frågor

Berätta hur ni känner kring det just nu. Berätta hur ni upplevde första kontakten eller tillfället Berätta hur ni uppfattar behovet av stöd från arbetsgivare i förhållande till att vård barn Berätta hur ni uppfattar behovet av kollegor i förhållande till att vård barn Berätta om eventuella andra behov som uppstår/blir tydligare/mindre i förhållande till att vård barn Berätta om hur ni upplever att vårda familjen runt barnet Berätta mer on hur du uppfattade det Vill du ge ett exempel? Hur tänker ni övriga det som…just berättat

Områden att beröra under intervjun:

Vad har varit/eller hade varit viktigt vid första tillfället? Vad blir viktigt efter ett tag? Svårigheter – utmaningar - möjligheter – positiva effekter Föreställningar Oro-trygghet Professionalitet I samband med insatsen - Efteråt

Avslutning

Något övrigt som ni tänkt före eller under intervjun som är viktigt men som inte kommit fram?

Intervjun avslutas med kort sammanfattning av bisittare och möjlighet för deltagare att respondera.

Interview guide: "Family interviews"

Introduktion med beskrivning av syfte för studien samt tillvägagångssätt för alla deltagare

Inledningsvis ett par bakgrundsfrågor om hur länge familjen varit hemma efter att barnet varit sjukt och hur länge familjen haft sjukvårdskontakt med anledning av barnets sjukdom.

Uppmaning: Inför det här samtalet har ni tagit bilder på ögonblick som är eller har varit viktiga för er med hänsyn till att få vård hemma. Vill ni berätta om bilderna för mig?

Familjemedlemmarna uppmuntras därefter till att beskriva sina bilder, hur de uppfattar bilden eller det bilden representerar och vad som fått dem att välja dessa bilder.

Familjemedlemmarna styr över vilka områden som kommer i fokus under samtalet och intervjuaren säkerställer att nedanstående områden berörs efter behov och möjlighet.

Det sjuka barnets behov, situation, upplevelse då sjukvård ges i hemmet Syskonens behov, situation, upplevelse då sjukvård ges i hemmet Föräldrars behov, situation, upplevelse då sjukvård ges i hemmet Familjeperspektivet då vård ges i hemmet Trygghet- Oro Tillgänglighet Behov och tillfredsställelse av kunskap och stöd

"Vardags-liv"

	Registreringsscher	ma för föräldrar e	fter sjukvårdsins	ats i hemmet	
	Kod Datum -		Mätti]	lifälle	
Fyll i efter var	rje besök av ASIH. Sätt e	en ring om det svarsal uppfattning av besö	ternativ som bäst bes iket.	kriver din och ditt barns	
1 Vad t Dåligt	yckte du om att o Mindre bra	ditt barn fick	sjukvård i hem Väldigt bra	met?	ora
2 Hur n	öjd var du med in	nsatsen i hemme	et?		
Mycket missnöjd	Missnöjd	varken nöjd eller missnöjd	Nöjd 1	Mycket nöjd	
3 Hur t	rvog känner du di	a med att ditt	harn fick sin	troind i hometa	
Myrakat			Darn rick sju	RVaru I Henunet?	
otrygg	Otrygg	eller otrygg	Ganska trygg	Mycket trygg	
4 Vad to	vokte ditt barn o	m att få ainka	ånd i benneta		
		m act ia sjukv	ard 1 hemmet?	_	
Daligt	Mindre bra	Bra	Väldigt bra	Utomordentligt b	ra
5 Hur ti	llfreds var ditt	harn med inca	teen i hommot?		
Mycket	Missnöjd	Varken nöjd	Nöjd	Mvcket nöid	
missnöjd	ställande	eller missnöjd			
6 Hur tr	waa var ditt bar	n mod att få a	·	- 1	
				<u> </u>	
otrygg	L] Otrygg	varken trygg eller otrygg	trygg	Mycket trygg	
7 Om du f	fick möjlighet ti	.ll ASIH igen.	Skulle du då v	älja det?	
	Ja Ne	j			
Kommentar					
Lämna i franke	erat adresserat kuvert	"ASIHBa Charlotte	Castor". Flera form	mulär kan sändas	

i ett kuvert. Posta eller lämna till ssk på ASIH som omberörjer att de sänds in.

Tack för din medverkan!



	Demografis	ka individ- ocl	h familjeka	raktäristika	
	Kod 🗌			Mättillfä	
LUND				matania	
UNIVERSITY					
Fyll i de uppgifter s finns möljighet att som eventuellt bid	om är relevanta för er lämna uppgifter om h rar i barnets vård.	r och er familjesituation. nela hushållet, andra vuxi	Fyll i ett formulär fö na sammanboende	ir varje vårdnadshavare. med vårdnadshavare och	På sidan två n andra vuxna
Vårdnadsha v Ålder	/are				
Utbildning o	ch yrke				
Utbildning (sa grund gymn högsł annat	ä <i>tt markering fö</i> iskola asieskola kola/universitet Kommentar	ir högsta genomf	örda utbildnin	g)	
För närvaran	de				
🗌 stude	ande				
arbets	sökande				
🗌 yrkesa	arbetande				3
🗌 yrkesa	arbetande men	frånvarande på ç	grund av barn	ets sjukdom	
🗌 yrkesa	arbetande men	frånvarande av a	annat skäl		
Aktuellt yrke:					
om yrkesarbe	etande:				
Uppskattad g	enomsnittslön <i>l</i>	före skatt om bar	net inte varit s	sjukt: (kr/mån)	
Uppskattad a	rbetstid (i %) o	m barnet <i>inte</i> var	it sjukt:	%	1. 1. 1
Uppskattad a	rbetstid (i %) o	m barnet vårdats	på sjukhus	1 %	
Uppskattad ti	d (i %) i arbete:	: senaste 6 mån	aderna		
		senaste månad	den	%	
		senaste veckar	า	%	
Andra inkon Erhåller du e	ister/ersättnin konomisk ersät	l gar ttning (ej lön)	∏ja ∏nej		
om ja:]a-kassa				
] bostadsbidrao	9			
] föräldrapenni	ng			
	ersättning för	vård av barn/allv	′arligt sjukt ba	irn	
	sjukskrivning				
	T VALODIOLAO				
F	Junderhåll				

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Demografiska individ- och familjekaraktäristika

De kommande frågorna gäller närstående boende på samma eller annan adress än det sjuka barnet samt hushållet.
Finns ytterligare person(-er) (ej vårdadshavare) med inkomst i hushållet ja nej om ja:
Uppskattad arbetstid (i %) om barnet <i>inte</i> varit sjukt: % Uppskattad arbetstid (i %) om barnet vårdats på sjukhus % Uppskattad tid (i %) i arbete: senaste 6 månaderna % senaste månaden % senaste veckan %
Total uppskattad disponibel inkomst för hushållet /månad (efter skatt)
Har andra närstående än de som bor med det sjuka barnet varit frånvarande från förvärvsarbete till följd av barnets sjukdom/vårdbehovjanej
vem/vilka (ange relation till ditt barn)
i vilken grad:något enstaka tillfälle någon gång / vecka någon gång/ månad
genomsnittligt antal timmar/tillfälle
uppskattad genomsnittlig månadslön <i>före</i> skatt (utan frånvaro)
Kommentar

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Demografiska individ- och familjekaraktäristika, uppföljning



			_		
n		-		-	

Mättillfälle

Fyll i de uppgifter som är relevanta för er och er familjesituation. Fyll i ett formulär för varje vårdnadshavare. På sidan två finns möljighet att lämna uppgifter om hela hushållet, andra vuxna sammanboende med vårdnadshavare och andra vuxna som eventuellt bidrar i barnets vård.

Vårdnadshavare

Nuvarande sysselsättning

För närvarande

studerande

arbetssökande

yrkesarbetande

yrkesarbetande men frånvarande på grund av barnets sjukdom

yrkesarbetande men frånvarande av annat skäl

Aktuelit yrke:

om yrkesarbetande:			
Genomsnittslön <i>före</i> skatt: (ki	r/mån)		
Uppskattad tid (i %) i arbete:	senaste månaden senaste veckan	% \\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\	
om ditt barn är fortsatt sjukt el	ller i behov av vård:		
Uppskattad arbetstid (i %) om	i barnet <i>inte</i> varit sjukt:	%	
Andra inkomster/ersättning Erhåller du ekonomisk ersättr	ar ning (ej lön) ja nej		
om ja: a-kassa			
socialbidrag	1		
ersättning för v	ård av barn/allvarligt sjukt ba	rn	
underhåll			



Demografiska individ- och familjekaraktäristika

De kommande frågorna gäller sjuka barnet samt hushållet.	närstående boende på samma	i eller annan adress än det
Finns ytterligare person(-er) (ej vårdadshavare) med inkom	st i hushållet 🔲 ja 🗌 nej
om ja: Genomsnittslön före skatt: (kr.	/mån)	
Uppskattad tid (i %) i arbete:	senaste månaden senaste veckan	% %
om ditt barn är fortsatt sjukt el	ler i behov av vård:	
Uppskattad arbetstid (i %) om	barnet <i>inte</i> varit sjukt:	%
Total uppskattad disponibel inl	komst för hushållet /månad (e	efter skatt)
Har andra närstående än de s förvärvsarbete till följd av barne	om bor med det sjuka barnet ts sjukdom/vårdbehov.	varit frånvarande från □ ja □ nei
om ja:		
vem/vilka (ange relation till ditt b	parn)	
i vilken grad:	ka tillfälle / vecka / månad	
genomsnittligt antal timmar/tillfäl	le	
uppskattad genomsnittlig månad (utan frånvaro)	Islön före skatt	
Kommentar		



	Demografiska individ- och familjekaraktäri	stika
	Kod Datum	Mättillfälle
Fyll i de uppgi	ifter som är relevanta för er och er familjesituation.	
<i>Barnet</i> Barnets ålde	er -	ar månad
Har barnet v Om ja:	vårdnadshavare på mer än en adress?	☐ja ∏nej
Bor barnet r <i>Om ja:</i>	egelbundet hos båda vårdnadshavare	🔲 ja 🔲 nej
Ange genom föräldern (ange i proce	nsnittlig fördelning av barnets boende hos vardera ent ex 20/80)	
Antal vuxna Antal vuxna <i>Om nej:</i> Antal vuxna	sammanboende med vårdnadshavare 1 sammanboende med vårdnadshavare 2 sammanboende med barnet	
Barnet har va	arit sjukt/haft symtom av aktuell sjukdom sedan:	└── ☐ födelse ☐ mer än ett år ☐ mer än en månad ☐ mindre än en månad ☐ inte längre sjuk
Barnets varda sjukdom/sym	ag har varit påverkad av tom/sjukvård i någon form sedan:	 ☐ födelse ☐ mer än ett år ☐ mer än en månad ☐ mindre än en månad ☐ ej relevant
Barnets symt	ombild/sjukvårdsbehov har förändrats senaste	☐ veckan ☐ månaden ☐ senaste 6 månaderna ☐ året
Kommentar		inte förändrats nämnvärt

Demografiska	individ-	och	familjekaraktäristika
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Har barnet tidigare varit inskrivet i barnomso i	rg ☐ ja ☐ nej Om ja: ☐ förskola ☐ familjedaghem ☐ fritidshem ☐ annat
Är barnet just nu inskrivet i någon barnomsorg <i>Om ja:</i>	∏ja ∏nej
Hur mycket har barnet i <i>genomsnitt</i> deltagit	senaste 6 månaderna 🔛 timmar / dag senaste månaden 🔛 timmar / dag senaste veckan 📄 timmar / dag
Har barnet tidigare gått i skola	☐ ja ☐ nej Om ja: ☐ grundskola ☐ grundsärskola ☐ gymnasium ☐ särskoleygmnasium
Är barnet just nu inskriven i någon skola	🗌 ja 🔲 nej
Om ja: I vilken omfattning har barnet i <i>genomsnitt</i> delta	git: senaste 6 månaderna 🗌 timmar / dag senaste månaden 📄 timmar / dag senaste veckan 📄 timmar / dag
I vilken utsträckning påverkas barnets vistelse i l av att ni får sjukvårdsinsatser i hemmet?	barnomsorg/skola påverkas inte alls minskar möjligheten att vara i barnomsorg/skola varierar ökar möjligheten vara i barnomsorg/skola ej aktuellt
Kommentar	





Demografiska individ- och f	amiljekaraktäristika
Kod LUND UNIVERSITY Datum	Mättillfälle
Fyll i de uppgifter som är relevanta för er och er familjes på samma adress som det sjuka barnet	ituation. Använd ett formulär/barn boende
Syskon samt övriga barn boende på samma	a adress
Syskonets ålder	år månad
Hur stor del av tiden bor syskonet på samma adress som det sjuka barnet:	 ☐ alltid ☐ 50% eller mer ☐ regelbundet men mindre än 50% ☐ sporadiskt
Om syskonet ibland bor i annat boende:	
Var bor syskonet mestadels då han/hon bor på adress än det sjuka barnet	annan hos annan vårdnadshavare i eget boende hos anhöriga/vänner varierar
l vilken utsträckning påverkas syskonets boend sjukvårdsinsatser i hemmet?	le av att ni får påverkas inte alls minskar möjligheten att bo hemma varierar ökar möjligheten att bo hemma ej relevant
Kommentar	



Demografiska individ- och familjekaraktäristika

Är syskonet just nu inskriven i någon barnomsorg		ja nej
	Om ja:	🔄 Förskola
		Familjedaghem
		Fritidshem
		🗌 Annat
I vilken omfattning har syskonet i genomsnitt deltagit	senaste: senaste	6 månaderna 🗌 timmar / dag månaden 🔲 timmar / dag
	senaste	veckan itimmar / dag
Är syskonet just nu inskrivet i någon skola		∏ia ∏nei
	Om ja:	grundskola
		 grundsärskola
		gymnasium
		Särskolegymnasium
Hur mycket har syskonet <i>i genomsnitt</i> deltagit i skolan:	senaste	6 manaderna 🛄 timinar / dag
	senaste	månaden
	senaste	veckan 📄 timmar / dag

Kommentar

