UiO University of Oslo

Ellen Katrine Kallander

Children affected by parental illness or parental substance abuse: young carers, well-being and quality of life

Thesis

January 2019

Faculty of Medicine

Series of dissertations submitted to the
Faculty of Medicine, University of Oslo

ISBN 978-82-8377-560-0

Cover: Hanne Baadsgaard Utigard.
Print production: Reprosentralen, University of Oslo.

Table of Contents

The attached questionnaire is limited to the version for children 8-13 years. However, there was also a version for the age group 14-18 years. The only difference between these two was the measure of social skills.

Acknowledgements

Professor Saul Becker's statement 'You need national research of international well-researched social problems to make changes in national policy' inspired me to pursue a Ph.D. The papers in my thesis benefited significantly from 25 years of work by Professor Saul Becker, the world's leading researcher on young carers. Special thanks to you. I am grateful for your co-supervision, for facilitating research on young carers, and especially your inspiration to achieve national research.

I would like to thank all the children and parents who participated in this study. This study would not be possible without them sharing their experiences with parental illness and the services they received in relation to their needs.

I would also like to thank all the institutions that made it possible for us to recruit these families as participants, including Akershus University Hospital, Vestre Viken Hospital Trust, Sørlandet Hospital (HF), Rogaland A-Senter, and Nordland Hospital Trust. I am grateful to the coordinators, research assistants, and Ph.D. students who collected the study data. I also thank the Regional Centre for Child and Adolescent Mental Health in Eastern and Southern Norway for technical data collection support and BarnsBeste - National Competence Network for Children as Next of Kin for ensuring that the participating children's interests were well taken care of. Additionally, I would like to thank the Research Council of Norway, the Norwegian Directorate of Health, and the participating partners that funded the multi-centre project.

I especially want to thank my previous main supervisor Professor Torleif Ruud. You supported me from the beginning of the Ph.D. project until after you retired and have been my co-supervisor to the end. You introduced me to quantitative research and greatly facilitated my doctoral thesis. Moreover, thank you so much for being the project leader of the multi-centre project. Your patience, positive attitude, and good sense of humour were magnificent during the research group meetings. Without you, there would be no Ph.D. and no multi-centre project. I am deeply indebted to you.

I am grateful to Ketil Hanssen-Bauer for taking over as main supervisor in middle of the last 2 intense years of my Ph.D. I want to thank you for your extraordinary patience with me during the supervision of my thesis, your thorough comments and feedback, and sharing your knowledge overall.

I am thankful to Bente Weimand, my co-supervisor, research group leader, and local co-ordinator for the multi-centre project. Your extraordinary supervisory skills, thoughtfulness, caring demeanour, enjoyment at work and in everyday life have made you a true friend to me.

Special thanks to Tove Bergh, co-ordinator of the personnel responsible for the children at Akershus University Hospital. I have many positive memories of your warmth, excellence, and lovely stories during our recruitment period. You are a wise lady and one of a kind. I would love to work with you again, anytime and anywhere!

Thank you to Betty Van Roy, my previous co-supervisor and current co-writer. Your support in the planning of my thesis, cheering me up and on, and providing me with the hope of accomplishment has been important during the whole process.

To my previous colleagues in the User's and Family Carers' Experiences research group, Olav Nyttingnes, Ann-Mari Lofthus, Trude Gøril Klevan, Ingrid Kyte Fjellestad, and Bente Weimand, thanks for all the support and inspiration during research meetings, in the Ph.D. office, and during casual events. I will miss you all. I also thank several other colleagues and especially the Ph.D. students at the R&D Department for your support. You are the best cheerleaders ever!

Thank you Åse Marit Hammersbøen for your librarian support throughout the whole process, you provided the very best service and knowledge.

I am thankful to all my colleagues and co-writers in the research group of the multi-centre project: Torleif Ruud, Bente Birkeland, Anne Faugli, Kristine Amlund Hagen, Anders Hellman, Marit Hilsen, Elin Kufås, Maren Løvås, Gro Christensen Peck, Åshild Skogerbø, Bjørg Eva Skogøy, Kristin Stavnes, Eivind Thorsen, Anne Schanche Selbekk, Bente M Weimand, and Jonas Christoffer Lindstrøm for statistical support. Every single one of you has been crucial. Together, we made it!

To my dear family: my brother and mother as well as my father who did not make it to see me finish my Ph.D. I know that you would be proud of me. You all have taught me the importance of empathy and care for others and supported me to go my own way. I am so grateful for your efforts.

Dear Stian, you met me during the most intense process of writing my papers and thesis. Thank you for all your love and support in everyday life. Your effort has been crucial. Love you!

Last but not at least, I wish to express my gratitude to my children Vilde and Eddie for their eternal patience during years of planning, recruitment, and the writing of my papers and thesis. I could not have done it without your patience, understanding, and support for the choices I have made. These choices included costs but have hopefully also accrued some benefits. So proud of you, love you deeply!

Akershus, January 2019
Ellen Katrine Kallander

Abbreviations

CAPI	Children affected by parental illness
CAPI model	Family ecology framework to guide research on parental illness, family functioning and children's well-being
CFA	The confirmatory factor analysis
FACES III	Family Adaptability and Cohesion Evaluation Scale
HRQoL	Health-related quality of life
ISEL-12	Interpersonal Support Evaluation List-12
KIDSCREEN	Quality of life measure named KIDCREEN-27
LoC	Locus of control
MACA	Multidimensional Assessment of Caring Activities
MI	Mental illness
PANOC	Positive and Negative Outcomes of Caring scales
PI	Physical illness
PQ-Y	Parentification Questionnaire – Youth
QoL	Quality of life
REK	The Regional Committee for Medical and Health Research Ethics
SA	Substance abuse
SCL-10	Hopkins Symptom Check List 10
SF-8	Health survey SF-8
SSRS	The Social Skills Rating System
YACS	The Youth Activities of Caregiving Scale
YC	Young carers
YCOPI	The Young Carer of Parents Inventory
YCPSS	Young Carer Perceived Stress Scale
YC-QST-20	Young Carers: Questionnaire and Screening Tool (Mental health)

Summary

In Norway and the Nordic countries more generally, the awareness of children affected by parental illness or substance abuse has increased during the last 10 years. There has also been a general shift from inpatient to outpatient care in public hospitals, and from public hospitals to primary health care. This shift has increased the number of parents who live at home with more severe illness while they are in active treatment. They need more informal and formal external care in their own homes. Until recently, care for the ill, disabled, or elderly within the family has been invisible and barely mentioned in public documents, statistics, or research reports. This applies even more for children's caregiving activities. In 2010, the Research Council of Norway called for research of this question, pointing out that 'little research has been conducted in this field, where children themselves serve as informants, and more insight is needed about which interventions and measures that provide effective help'. The main aims of the papers discussed in this thesis have been to explore:

- The extent and nature of the children's caring activities
- The positive and negative outcomes of the children's caring activities
- Factors associated with the children's quality of life (QoL)

Methods

We used data from a larger cross-sectional multi-centre project, which recruited parents who were inpatients or outpatients in specialised health services in five public hospitals in three of the four health regions in Norway. Via the patients, we recruited one child from each family. The inclusion period was 20 months (May 2013–December 2014). Project staff and PhD students, who had received training in conducting interviews, collected the data. They met the family at a time and location chosen by the family, which was usually in the family's home. The present study used data from 246 children aged 8-18 and from 238 of their parents with either severe physical illness (*N* = 135), mental illness (*N* = 75), or substance abuse (*N* = 28).

Results

The first paper reports that children of a parent with a physical or mental illness or substance abuse problem perform more caring activities than children in general. The parents reported limited access to formal external care. More than two of ten parents with physical or mental illness reported that their children provided increased caring activities due to parental illness, particularly personal care. Parents with substance abuse reported rarely that their children provided increased caring activities due to parental substance abuse. The extent of children's caring activities did not differ between the parental illness groups, except that the children reported more emotional care for the parent if the parent had a physical illness than if the parent had an mental illness. Twenty-one percent of the children were making sure that the ill parent took their medicines. Extent of the children's caring

activities were negatively associated with parents' self-reported physical health status and positively associated with the children's self-reported social skills and external locus of control. The nature of caring activities was associated with several factors reported by the children (the children's gender, age, social skills and external locus of control) and several factors reported by the ill parent (type of illness, parental physical health status and family income).

The second paper reports that the majority of the children reported positive outcomes from providing care. However, nearly half of the children reported stress, while 10% reported negative outcomes at a clinical level of concern. Neither positive nor negative outcomes differed between the children in the three parental illness groups. Positive outcomes were positively associated with the children's self-reported social skills, and negatively associated with provision of household management and personal care. Negative outcomes were positively associated with the children's self-reported external locus of control, provision of financial and practical management and personal care. Moreover, negative outcomes were negatively associated with social skills.

The third paper reports that the children's self-reported QoL was positively associated with the ill parent's self-reported physical health status, that the child is a boy, the children's self-reported social skills, that other adults take over the responsibilities for the ill parents, provision of health care for the ill parent, and positive outcome of the caregiving. QoL was negatively associated with children's age, self-reported increased responsibilities due to parental illness, provision of emotional care, negative outcome of caregiving and external locus of control.

Across the three papers four factors seems to be particularly important for the children when parents are ill. The first, children's self-report of good social skills, was associated with both that they reported more caregiving, more positive outcomes of their caregiving, and better QoL. The second, children's self-report of more external locus of control, was associated with both that they reported more caregiving, more negative outcomes of caregiving, and reduced QoL. The third, ill parent's report of a reduced physical health status was associated with both that the children reported more caregiving, and reduced QoL. The fourth, the children's negative outcome of caregiving was associated with reduced QoL, while positive outcome of caregiving was associated with increased QoL.

Conclusion and implications

We found that the children affected by parental illness or substance abuse perform more caregiving at home and for their parent than other children do. More than half of the children experienced more responsibilities at home due to parental illness and two thirds for parents with physical illness. One third experienced too much responsibility due to parental illness. Poorer QoL was associated with older age of the children, being girl, that the child reported more responsibility due to parental illness, and more negative outcomes of their caregiving. Better QoL was associated with the child experiencing that other adults took over the responsibilities that the ill parent usually had, the child reported provision of health care to the ill parent and more positive outcomes of caregiving.

Our results suggest that professionals within the health and child protection services should provide a more comprehensive assessment of the needs of the parents and children, regardless of the type of parental illness (i.e. physical, mental or substance abuse). Furthermore, this should include whether the parents' physical health status may negatively influence their ability to perform daily activities. Our findings also suggest that interventions to meet both the children's and families' reports of unmet needs and to reduce the children's negative outcome of increased responsibilities are particularly important and should thereby be developed and tested. In addition, the professionals within the health and child protection services should recognize the children's social skills, that their contributions at home and in the family are important and the positive impacts that the children's caregiving may have on their QoL. In addition, these professionals need to be aware of and prevent the potential negative outcomes for the children. Our findings suggest that assessment of QoL could identify children who struggle the most with parental illness or parental substance abuse. The findings suggest that young Norwegian carers need the same legal rights to professional information, respite and carer support as adult carers have. These entitlements are especially important because children are more developmentally vulnerable and need to be secured their school achievements and education. The findings across the three papers indicate a prevalence of 10-12% young carers who conducted extensive care based on the Norwegian Directorate of Health definition for adult carers with extensive care and the right to carers support.

This is a large study with a broad inclusion of participant across Norway, which included children as informants and used well-established measures. There were several challenges related to recruitment that may have led to a biased sample of children affected by parental illness in this study. However, most probably the situation of the families, the extent and outcome of caring activities conducted by the children and their QoL are probably less positive than the study suggests.

Further studies should assess the positive and negative outcomes of children's caring activities, particularly the impact of the children's caregiving on their QoL, health, school achievements and education. We need studies of the unmet needs of the children and their families regarding informal and formal external care, health care, and carer support (e.g. information, guidance and respite). We should evaluate the discrepancy between interventions for adult carers and young carers in Norway in relation to the UN Convention on the Rights of the Child.

Norsk sammendrag [Summary in Norwegian]

I Norge og de nordiske landene generelt har oppmerksomhet rundt barn som er påvirket av foreldres sykdom eller foreldrenes rusmisbruk økt de siste 10 årene. Det har vært en generell dreining til mindre døgnbehandling og mer poliklinisk behandling i spesialisthelsetjenesten, og til at mer behandling følges opp av primærhelsetjenesten. Dette har økt omfanget av foreldre som lever med mer alvorlig sykdom hjemme mens de er i aktiv behandling. Dette vil naturlig nok øke behovet for både hjemmebaserte tjenester fra kommunene og hjelp fra pårørende. Inntil nylig har pårørendes ulønnede omsorgsarbeid for syke, funksjonshemmede eller eldre i familien vært lite synlig og i relativt liten grad nevnt i offentlige dokumenter, statistikker eller forskningsrapporter. Dette gjelder enda mer for barn som er pårørende og utfører omsorgsarbeid. Forskningsrådet utlyste i 2010 midler til forskning om barn som pårørende. De begrunnet det med at det fantes lite forskning om dette der barn selv var informanter og at behovet for mer innsikt om hvilke tiltak som gir effektiv hjelp var stort. Hovedformålet med artiklene som diskuteres i denne avhandlingen har vært å undersøke:

- Omfanget av og typer omsorgsoppgaver barn bidrar med
- De positive og negative konsekvensene av barnas omsorgsoppgaver
- Hvilke faktorer som har sammenheng med barnas livskvalitet (QoL)

Metoder

Vi brukte data fra en større multisenterstudie med et tverrsnittsdesign. Vi rekrutterte foreldre som var pasienter i døgnavdeling eller poliklinikk i spesialisthelsetjenesten i fem helseforetak i tre av de fire helseregionene i Norge. Via pasienten rekrutterte vi ett barn fra hver familie. Inklusjonsperioden var 20 måneder (mai 2013–desember 2014). Innsamlingen av data ble utført av prosjektmedarbeidere eller stipendiater som hadde fått opplæring i gjennomføring av intervjuer. De møtte familien på et tidspunkt og sted valgt av familien, vanligvis etter skoletid og i familiens hjem. Studien brukte data fra 246 barn i alderen 8-17 år og fra 238 foreldre med enten alvorlig fysisk sykdom (*N* = 135), psykisk lidelse (*N* = 75) eller rusmisbruk (*N* = 28).

Resultater

Artikkel I rapporterer at barn som har en forelder med fysisk sykdom, psykisk lidelse eller rusmisbruk utfører mer omsorgsoppgaver enn barn i den generelle befolkningen. Foreldrene rapporterte svært begrenset tilgang til hjemmebaserte tjenester. Mer enn to av ti foreldre med fysisk sykdom eller psykisk lidelse rapporterte at deres barnas utførte mer omsorgsoppgaver på grunn av at forelderen var syk, særlig hjelp til personlig pleie. Foreldre med rusmisbruk bekreftet i liten grad at barna utførte mer omsorgsoppgaver på grunn av at forelderen misbrukte rusmidler. Det totale omfanget av barnas omsorgsoppgaver var ikke forskjellig mellom sykdomsgruppene, men barna ga mer emosjonell omsorg til foreldre med fysisk sykdom enn til foreldre med psykisk lidelse. Tjue-en prosent av barna passet på at syk forelder tok medisinene sine. Omfanget av barnas omsorgsoppgaver hadde negativ sammenheng med foreldrenes selvrapporterte fysiske helsetilstand og positiv sammenheng med barnas selvrapporterte sosiale ferdigheter og følelse av mangel på kontroll. Type omsorgsoppgaver hadde positiv sammenheng med flere faktorer som ble rapportert av barna selv (barnets kjønn, alder, sosiale ferdigheter og følelsen av mangel på kontroll) og flere faktorer som ble rapportert av den syke forelderen (fysiske helsetilstand, familieinntekt og sykdomstype).

Artikkel II rapporterer at flertallet av barna rapporterer det som positivt å bidra med omsorg for den syke forelderen og i familien. Likevel, nesten halvparten av barna rapporterte stress som følge av omsorgsoppgaver, mens 10 % rapporterte negative konsekvenser på et bekymringsfullt nivå. Verken positive eller negative konsekvenser av barnas omsorgsoppgaver var forskjellig mellom sykdomsgruppene. Barnas selvrapporterte positive konsekvenser av omsorgsoppgavene hadde en positiv sammenheng med deres selvrapporterte sosiale ferdigheter. Barnas selvrapporterte negative konsekvenser av omsorgsoppgavene hadde en positiv sammenheng med barnas følelse av mangel på kontroll, at de utførte økonomiske og praktiske oppgaver og personlig pleie av forelderen. Videre hadde barnas selvrapporterte negative konsekvenser av omsorgsoppgavene en negativ sammenheng med barnas selvrapporterte sosiale ferdigheter.

Artikkel III rapporterer at barnas selvrapporterte livskvalitet hadde en positiv sammenheng med den syke forelderens fysiske helsetilstand, at barnet var en gutt, med barnets selvrapporterte sosiale ferdigheter, erfaringer med at andre voksne tar over den syke forelderens ansvar, at barnet følger opp den syke forelderens helse og positive konsekvenser av omsorgsoppgavene. Barnas selvrapporterte livskvalitet hadde en negativ sammenheng med barnets alder, at barnet rapporterte økt ansvar på grunn av forelderens sykdom, at de ga emosjonell omsorg til den syke forelderen, negative konsekvenser av omsorgsoppgavene og følelse av mangel på kontroll.

På tvers av de tre artiklene er det særlig fire faktorer som ser ut til å ha betydning for barna når foreldrene er syke. Den første, barns selv-rapport av gode sosiale ferdigheter, fant vi at hadde sammenheng med både at barna rapporterer mer omsorgsarbeid, mer positive konsekvenser av omsorgen og bedre livskvalitet. Den andre, barns selv-rapport av mer følelse av mangel på kontroll, hadde sammenheng med både at de rapporterte mer omsorgsarbeid, mer negative konsekvenser av omsorgen og redusert livskvalitet. Den tredje, syke foreldres rapport av at de hadde en dårligere fysisk helsetilstand hadde sammenheng med både at barnet rapporterte mer omsorgsarbeid, og redusert livskvalitet. Den fjerde, barnas negative opplevelse av omsorgsoppgavene hadde sammenheng med redusert livskvalitet, mens deres positive opplevelse hadde sammenheng med bedre livskvalitet.

Konklusjon og implikasjoner

Vi fant at barns omsorgsarbeid øker når foreldre er syke eller har et rusmisbruk. Mer enn halvparten av barna opplevde økt ansvar på grunn av foreldrenes sykdom, der dette ble rapportert av to tredjedeler av barna med alvorlig fysisk syke foreldre. En tredjedel av barna som pårørende opplevde for mye ansvar knyttet til at foreldrene var syke. Dårligere livskvalitet hadde sammenheng med at barnet var eldre, at barnet var en jente, at barnet rapporterte at de hadde mer ansvar på grunn av forelderens sykdom, og at de rapporterte mer negative konsekvenser av omsorgen. Bedre livskvalitet hadde sammenheng med at barnet rapporterte at andre voksne tok over det ansvaret den syke forelder vanligvis hadde, at barnet rapporterte at de ga helsehjelp til forelderen og at opplevde mer positive konsekvenser av omsorgen.

Våre resultater tyder på at ansatte innen helsevesenet og barnevernet bør gjøre mer omfattende vurdering av foreldre og barns behov, uansett hva slags sykdom foreldre har (fysisk sykdom, psykisk lidelse eller rusmisbruk). Videre, bør dette inkludere om forelderen har en redusert fysisk helsetilstand som kan medføre manglende kapasitet til å utføre daglige aktiviteter. Våre funn tyder også på at tiltak for å møte barnas og familiens egenrapporterte udekkede behov og for å redusere barnas negative konsekvenser av økt ansvar er særlig viktig og bør utvikles og testes. I tillegg bør ansatte innen helsevesenet og barnevernet anerkjenne barnas sosiale ferdigheter, at deres bidrag hjemme og i familien er viktig og de positive konsekvenser omsorgsoppgaver kan ha for deres livskvalitet. I tillegg bør disse ansatte være oppmerksomme på og forebygge de potensielle negative konsekvensene for barna. Våre funn tyder på at kartlegging av livskvalitet kan identifisere de barna som strever mest i forbindelse med foreldrenes sykdom eller rusmisbruk. Resultatene tyder på at de barna som utfører omsorgsarbeid, bør få samme rett til pårørendestøtte i form av informasjon, veiledning, støtte og avlastning som voksne pårørende. Dette er spesielt viktig fordi barn er utviklingsmessig mer sårbare og trenger at skoleprestasjoner og utdanning sikres. På tross av mulig skjevhet i utvalget indikerer funnene i de tre artiklene at 10-12 % av barn som pårørende utfører særlig tyngende omsorgsarbeid basert på definisjon fra Helsedirektoratet for voksne pårørende med rett til pårørendestøtte.

Dette er en stor studie med en bred inklusjon av deltagere fra flere steder i Norge, hvor barna ga informasjon selv og hvor vi brukte veletablerte spørreskjema. Det var flere utfordringer knyttet til rekrutteringen som kan ha ført til et skjevt utvalg av barn med syke foreldre, men hvis det foreligger utvalgsskjevheter så er det mest sannsynlig at familienes situasjon, omfanget og konsekvenser av omsorgsoppgaver utført av barna og barnas livskvalitet er mindre positive enn det studien antyder.

Videre studier bør undersøke positive og negative konsekvenser for barn som utfører omsorgsoppgaver, spesielt hvordan det påvirker barns livskvalitet, helse, skoleprestasjoner og utdanning.

Vi trenger studier av de udekkede behovene disse barna og familiene har for uformell og formell støtte utenfra, tilgang på helsetjenester og tilgang på pårørendestøtte som informasjon, veiledning, støtte og avlastning. Forskjellen i tiltak for voksne og barn som er pårørende med særlig tyngende omsorgsarbeid i Norge bør utforskes med utgangspunkt i FNs barnekonvensjon.

List of Papers

Paper I:

Kallander EK, Weimand BM, Becker S, Van Roy B, Hanssen-Bauer K, Stavnes K, Faugli A, Kufås E, Ruud T. **Children with ill parents: extent and nature of caring activities.** Scandinavian Journal of Caring Sciences 2017. http://dx.doi.org/10.1111/scs.12510

Paper II:

Kallander EK, Weimand BM, Ruud T, Becker S, Van Roy B, Hanssen-Bauer K. **Outcomes for children who care for a parent with a severe illness or substance abuse.** Child & Youth Services 2018. https://doi.org/10.1080/0145935X.2018.1491302

Paper III:

Kallander EK, Weimand BM, Hanssen-Bauer K, Lindstrøm JC, Van Roy B, Ruud T. **Factors associated with quality of life for children affected by parental illness or parental substance abuse** [Submitted] Scandinavian Journal of Caring Science.

1 Background

In 2010, Norway amended the Health Personnel Act to require health care personnel to clarify whether patients have children and to ensure that the children's need for information and appropriate services are met. This amendment included children younger than 18 who are next-of-kin to parents with severe physical illness, mental illness, or substance abuse (Helsedirektoratet, 2010, p. 103; Helsepersonelloven, 1999). This thesis is about how parental illness affect children aged 8–18 years.

1.1 Context of this research

In 2011 the Research Council of Norway (2011) launched a research programme called 'Children as Relatives' (BARN) with the following objectives:

> Children whose parents are seriously ill or are substance abusers have a higher risk of developing mental health and social problems. Little research has been conducted in this field, where children themselves serve as informants, and more insight is needed about which interventions and measures provide effective help. Other challenges in this context include identifying the children involved, establishing adequate, integrated services, and ensuring continuity in follow-up of affected families. Projects under the BARN research initiative must incorporate children and family perspectives.

This thesis is part of a larger multi-centre project that received primary funding from this BARN research programme. The aim of the larger project was to provide new knowledge about the prevalence, situation, and adjustment of children aged 0–18 years whose parents were patients in specialised health services. The project included the experiences and descriptions of the family situation reported by both the children and parents. Further, the larger project examined how well the specialised health services identified the children, and to what extent the legislative amendment from 2010 had been implemented. In addition to the primary funding from The Research Council of Norway, the project was also funded by the Norwegian Directorate of Health so that it could advise how health services can help the patients' children and other family members. Further funding was received from the health trusts involved. They contributed with personnel to the project research group, to the recruitment of study participants, and interviewers. The National Competence Network for Children as Next of Kin, named BarnsBeste, ensured that the participating children's interests were properly taken care of in this larger project.

1.2 Overall aims of this thesis

This thesis uses a subsample from the larger project to investigate how parental illnesses affect children aged 8–18 years. The main aims of the papers included in this thesis have been to explore:

- The extent and nature of the children’s caring activities (paper I)
- The positive and negative outcomes of the children’s caring activities (paper II)
- Factors associated with the children’s quality of life (QoL) (paper III)

The more specific aims of the three papers are outlined in Chapter 2: Aims of the three papers.

1.3 Core concepts used in this thesis

Different academic and clinical disciplines (i.e. psychology, sociology, family therapy) have understood and investigated how parental illness affects children within a variety of paradigms. The use and definitions of concepts has therefore varied a lot. In the present work, I have been inspired by the family ecology framework that Pedersen and Revenson (2005) developed to guide research on parental illness, family functioning and children’s well-being, by the OECD’s (2016) operationalisation of the concept of children’s well-being, and the research of young carers. Further in this chapter, I will first give a short description of how I use some of the core concepts in this thesis, and then give an introduction to this research field.

Children affected by parental illness (CAPI)

‘Children affected by parental illness’ (CAPI) is a concept often used internationally. In this thesis, parental illness includes severe physical illness, any kind of mental illness, or any kind of substance abuse that a parent has for a shorter or longer time period. Parent includes any adult in the household who has a parental role regarding one or more children. The children are younger than the age of 18 years and living in the same household. In this thesis, I have investigated a subgroup of these children, i.e. children aged 8–18 years.

Young carers

I use the following definition of the concept *young carers* from an updated study by the UK’s Department of Education, because it recognises the most important dimensions of caring (cited from Cheesbrough, Harding, Webster, & Aldridge, 2017, p.14; Clay, Connors, Day, Gkiza, & Aldridge, 2016, p. 18):

> A young carer is a child/young person under the age of 18 who provides care in, or outside of, the family home for someone who is physically or mentally ill, disabled or misusing drugs or alcohol. The care provided by children may be long or short term and, when they (and their families) have unmet needs. Caring may have an adverse impact on children’s health, well-being and transitions into adulthood.

Children's well-being

There are several definitions of the concept of children's well-being. The concept is closely related to and has dimensional overlaps with the concept of children's QoL. Both concepts have been developed within separate traditions, most often identified as multi-dimensional, and also combined. This thesis is inspired by the OECD (2016), which has operationalised the concept of children's well-being in two broad groups:

1) The well-being conditions of families where children live, which relate to the level of family income, housing conditions and the quality of the environment. In this thesis the well-being conditions of the families are limited to and measured by family socio-demographics, family functioning, parental illness characteristics and severity, and access to care and social support.

2) Child-centred well-being factors, which include their own health status, educational and social outcomes, as well as their own subjective perceptions of quality of life (QoL). In this thesis the child-centred well-being factors are limited to and measured by child characteristics, daily hassles such as extent and nature of caring activities (MACA), children's stress response such as positive and negative outcome of caregiving (PANOC), and QoL (KIDSCREEN).

Children's quality of life (QoL)

The *concept children's QoL* is often described as one aspect of *children's well-being*. The two concepts are closely related and even overlapping: some of the dimensions of children's QoL are named "well-being", e.g. "children's psychological well-being". In this thesis and included papers the QoL construct is understood as multidimensional, and covers physical, emotional, mental, social, and behavioural components of well-being and functioning (Ravens-Sieberer, Herdman, et al., 2014, p.792). Specifically, children's QoL in this thesis is measured in the following dimensions: physical well-being, psychological well-being, parent relations and autonomy, social support and peers, and school environment (KIDSCREEN) (Ravens-Sieberer et al., 2007). This definition of QoL is chosen because it includes several principal dimensions of impact of parental illness and outcome of caring activities (Schlarmann, Metzing-Blau, & Schnepp, 2008), and the measurement due to its broad assessment of QoL including positive and negative aspects of life (Wallander & Koot, 2016).

The core concepts used in this thesis, CAPI, young carers, well-being and QoL will be more thoroughly described in the subchapters in the thesis background chapter.

1.4 Children affected by parental illness (CAPI)

The research of outcome for CAPI has been investigated from various theoretical perspectives and research paradigms since the 1960s. From the 1990s there have been changes in perspectives on children in research which have impacted beneficially on the research of CAPI. This subchapter will particularly have a focus on the changes in research of CAPI from the last 50 years, into late in the 2010s.

1.4.1 Do children inherit their parent’s illness?

Since the early 1960s, there has been a broad spectrum of research on how children’s mental health is affected by having a mentally ill parent. This research has most often been based on parental reports and has been analysed within a deviation and risk and resilience paradigm (Gladstone, Boydell, & McKeever, 2006; Ytterhus, 2012). Recent reviews in this field have indicated that the children of parents with mental illness are at a greater risk for adjustment problems, depression, and other psychiatric disorders (Beardslee, Gladstone, & O'Connor, 2011; Beardslee, Versage, & Giadstone, 1998; Loechner et al., 2018). This research paradigm has mainly investigated whether the children develop the same mental health problems or illness as their parent. The children’s alcohol abuse is the most explored outcome from parental alcohol abuse (Rossow, Felix, Keating, & McCambridge, 2016). One exception has been other types of substance abuse such as drugs, where the findings have suggested increased neglect and maltreatment of the children (Backett-Milburn & Jackson, 2012; Backett-Milburn, Wilson, Bancroft, & Cunningham-Burley, 2008; Neger & Prinz, 2015; Staton-Tindall, Sprang, Clark, Walker, & Craig, 2013).

Through the 1960s to the 1990s, the literature on developmental psychology and family therapy has described children’s caregiving for parents and siblings in terms of parentification as pathological, while the literature in sociology has described such caregiving as deviant (Winton, 2003). These assumptions and different theories of children’s caregiving are based on retrospective data from psychotherapy of adults who had parents with substance abuse or depression. The data suggested that they often had been parentified (Chase, Deming, & Wells, 1998; van der Meiden, Noordegraaf, & van Ewijk, 2018; Van Parys & Rober, 2013). The parentified child takes on extensive responsibilities for a parent or a sibling, both at a practical and an emotional level. Within developmental psychology, parentification is understood as a reversal of the parent and child roles and creates a risk for insecure attachment patterns and relation disorder for the children (Bowlby, 1977; Byng-Hall, 2002; Kelley et al., 2007). However, this research paradigm has seldom been based on the children’s own self-reports (Van Loon, Van de Ven, Van Doesum, Hosman, & Witteman, 2017), nor the mother’s self-reports (Vulliez-Coady, Obsuth, Torreiro-Casal, Ellertsdottir, & Lyons-Ruth, 2013; Vulliez-Coady, Solheim, Nahum, & Lyons-Ruth, 2016).

1.4.2 New perspectives on children's participation in research

From the early 1990s, 'new' social studies within childhood sociology understood children as social actors and complex young persons who were crucial informants of their own situation and possessed competencies and vulnerabilities linked to their developmental stages. This is in contrast to the early developmental psychology's more traditional image of children as passive, developing, and 'unfinished' persons (James, Jenks, & Prout, 1999; Prout & James, 2003). This notion may also have influenced research within several fields of psychology. Hundeide (2003) has pointed out that 'new' developmental psychology studies of children that take an interpretive approach should be based on the child's experience of situations and of their own alternatives. According to Hundeide (2003), the perspective is important because it captures the complex conditions that affect a person's actions and choices. Moreover, he has also pointed out that the children's abilities and skills therefore should not be measured without including these premises.

Since the beginning of the 2000s, there has been an increase in studies of children who live with parents with physical illness. This research is different from the other two groups of parental illnesses, namely mental illness and substance abuse, in that it has not explored parental physical illness as something the children 'inherit' or 'learn' (Ytterhus, 2012). Research of parental physical illness has also focused on the mental health of children but has more often included the children's perspective. However, several researchers within this field have argued that more sensitive measures of contextual issues are needed to understand the impact of parental physical illness on the children (Bogosian, Moss-Morris, Bishop, & Hadwin, 2014; Gladstone et al., 2006; Morley, Selai, Schrag, Thompson, & Jahanshahi, 2010; Osborn, 2007; Pakenham, Bursnall, Chiu, Cannon, & Okochi, 2006). According to Osborn (2007), there is limited evidence that externalised symptoms in children, such as problem behaviour, are the outcome of parental physical illness. Research of children affected by parental mental illness or parental substance abuse has often focused on the children's future development (well-becoming), while research of children affected by parental physical illness has often focused on the children's lives (well-being) (Ytterhus, 2012).

Children as informants

Mothers are most often the main source of information about the child in mental health research and clinical work for children and adolescents. Proxy mental health measures where mothers rate their children have been used more often than information directly from the children in studies on the impact of parental illness (Backett-Milburn et al., 2008; Gladstone et al., 2006; Sieh, Meijer, Oort, Visser-Meily, & Van der Leij, 2010; Östman, 2008). Descriptions of the impacts of parental illness on the children's mental health or quality of life will often differ systematically between the child, a parent, or a teacher (Bee, Berzins, Calam, Pryjmachuk, & Abel, 2013; Berg-Nielsen, Solheim, Belsky, &

Wichstrom, 2012; Eiser & Varni, 2013; Jonsson et al., 2017; Jozefiak & Kayed, 2015; Quitmann, Rohenkohl, Sommer, Bullinger, & Silva, 2016; Wallander & Koot, 2016). Discrepancies between children's self-report and parent's report about the children's mental health have been repeatedly acknowledged in the literature and are often understood as part of a proxy problem (Sattoe, van Staa, Moll, & On Your Own Feet Research Group, 2012). This may limit the generalisability of the results to a broader target population (Najman et al., 2000; Sieh, Meijer, Oort, et al., 2010). A Norwegian study has demonstrated that the discrepancies between the parents' and children's evaluations of needs for services underline the importance of paying attention to child reports, particularly when parents do not identify children's needs (Van Roy, Groholt, Heyerdahl, & Clench-Aas, 2010).

Depressed mothers rate the youth's behavioural problems less reliable than not-depressed mothers (Berg-Nielsen, Vika, & Dahl, 2003; De Los Reyes, Goodman, Kliewer, & Reid-Quinones, 2008; Friedlander, Weiss, & Traylor, 1986; Jeske, Bullinger, & Wiegand-Grefe, 2011; Najman et al., 2000; Najman et al., 2001; Ordway, 2011; Quitmann, Kriston, Romer, & Ramsauer, 2012). I found only one paper reporting from a study about the QoL in children affected by parental substance abuse (Comiskey, Milnes, & Daly, 2017). This study used parent's reports and found that the children had higher levels of QoL than European norm data. Hence, it may be more important to include children as informants in research when a parent is physically ill, mentally ill, or abuse alcohol or drugs.

1.4.3 Similar impacts of the different types of parental illnesses?

With knowledge about common, and illness-specific, needs among children affected by parental illness, and about factors that are associated with negative and positive outcomes for the children, more targeted interventions may be developed.

From the late 2000s, quantitative studies have begun to explore whether the impact of parental illness are more similar across the different types of illnesses. These explorations are based on samples that include both parental physical illness and mental illness. Only a few samples include parental substance abuse, alcohol, or drugs. To my knowledge, there are only two studies that explore how the children's outcomes differ across parental physical illness (cancer) and mental illness (Giannakopoulos et al., 2009; Krattenmacher et al., 2014). Krattenmacher and colleagues (2014) have indicated that the type of parental disease and the parent's subjective health status had no direct effect on children's adjustment. Giannakopoulos and colleagues (2009) have found that parents' good mental health status was associated with better quality of life for adolescents. To my knowledge, there is only one study which includes parental substance abuse in addition to physical and mental health when studying associations with the children's adjustment. This study found that the risk of adjustment problems for the children was elevated if the ill parent was mentally ill or abused substances (Pakenham & Cox, 2014).

The research on children's caregiving and outcomes, particularly by Pakenham and colleagues (2010a, 2010b; 2006; 2007; 2014, 2015, 2018), has studied differences across parental physical illness, mental illness, and substance abuse in greater detail than the studies of association between children's adjustment and parental illness. One study has demonstrated increased levels of caregiving compared to children with healthy parents (Pakenham et al., 2006). Two studies have found that children with parental mental illness reported more negative outcomes from caregiving than children with parental physical illness (Ireland & Pakenham, 2010b; Pakenham et al., 2006). One study which covered parental substance abuse in terms of alcohol or drugs has demonstrated that illness type had no differential effect on the outcome of caregiving, but intensified when the ill parent had more than one type of illness (Pakenham & Cox, 2015).

1.4.4 Do children affected by parental illness become young carers when the families' needs are not met?

There are also qualitative studies that have explored children's caregiving due to the families' unmet needs when a family member have physical or mental illness, disability, or substance abuse disorder (Aldridge, 2017; Aldridge & Becker, 1999; Chikhradze, Knecht, & Metzing, 2017; Clay et al., 2016; Leu & Becker, 2016; Rose & Cohen, 2010). These studies are within the 'new' sociology childhood tradition and are known as the young carers research paradigm (S. Becker, 2007), which I will describe more thoroughly in chapter 1.6. To my knowledge, there is no qualitative research of the outcomes of parental illness for children that include more than one of the illness groups (physical, mental, or substance abuse) which is not framed in this research paradigm.

1.5 Research on parental illness, family functioning and children's well-being

This subchapter will particularly have a focus on research literature relevant for the selection of the independent and dependent variables for CAPI and the three papers (I-III) of the thesis.

In this thesis and the included papers the family ecology framework to guide research on parental illness, family functioning and children's well-being (the CAPI model) developed by Pederson and Revenson (2005) was important for the selections of the independent and dependent variables. Based on general system theory (Von Bertalanffy, 1968) and human ecology (Bronfenbrenner, 1977), their aim was "understanding children's reactions to parental illness" by evaluating previous research so that effective interventions could be developed for families that experienced parental illness

(Pedersen & Revenson, 2005). In the CAPI model, parental illness is hypothesised to affect family functioning (e.g. family cohesion and parental capacity) and children's well-being (e.g. child's everyday life with peers, school, and family relationships) indirectly through mediators at the individual level (e.g. children's daily hassles and stress response) and the family level (e.g. family role redistribution). Mediators at individual and family levels may be affected by a number of other more contextual moderators on the same levels (e.g. the child and parent's age and gender, coping style, and psychological resources). Also, differences in illness characteristics (e.g. diagnosis, severity, duration, unpredictability and level of stigmatisation) may affect the children differently. There are also relevant moderators external to the family (e.g. social support, access to care, and cultural norms) that may affect the children. I will in the following describe more deeply how these factors previously have been researched and how the factors are defined and assessed in the thesis and papers included. I will refer to these mediators and moderators from Pedersen and Revenson (2005) as factors or independent variables.

1.5.1 Family role redistribution and family functioning

The authors found that family role redistribution was associated with the illness effects on family functioning, e.g. family cohesion and parental capacity (Pedersen & Revenson, 2005). To redistribute the roles in the family is the most common coping mechanism used by families experiencing parental illness (Pakenham & Cox, 2012b; Rolland, 1999; Sieh, Visser-Meily, Oort, & Meijer, 2012). The authors (2005) point out that the family system literatures describe well-functioning families as cohesive, flexible, and self-reflective. According to Pedersen and Revenson (2005), good family functioning during parental illness includes high levels of communication and the parents' ability to redistribute the roles within the family in ways that do not compromise the children's development. When an ill parent is not capable of fulfilling the roles he or she previously had, other family members may be required to provide the tasks included in that role (Pedersen & Revenson, 2005).

The term 'family functioning' in this thesis is measured by parent's report of family cohesion (paper II – III) and the parents' capacity (paper I-III) to fulfil the roles that they previously did. 'Family cohesion' in this thesis is defined as separation or connection of family members to the family. We assessed this by questions about whether the family members ask each other for help (Olson, 1986). Family cohesion is in this thesis also defined as the parents' ability to perform role redistribution within the family, which may increase the ill parent's access to informal care within the family (paper I). The term 'parenting capacity' in this thesis and the included papers address the degree to which the parent's illness negatively influence engagement in practical work at home, ensure the child's needs related to school and leisure time, emotional support, to maintain structure in everyday life and familial social activities. The term 'family role redistribution' in this thesis denotes the parent's perception and recognition of the children's possibly increased provision of caring activities due to parental illness and unmet needs due to lack of access to care (paper I). Furthermore, children's self-reported perception of taking on increased responsibility due to parental illness and their perception of other adults who provide the roles or responsibilities the ill or substance abusing parent usually had when they were not ill (paper III). Family role redistribution (Pakenham & Cox, 2015; Sieh, Visser-Meily, & Meijer, 2013a), will be described more thoroughly in the subchapter 1.6 about young carers.

There are two main theoretical perspectives on family functioning. The first perspective is result oriented and includes family characteristics such as intimacy, adaptability, and communication (Dai & Wang, 2015). The second perspective is process oriented and covers the extent to which the family has fulfilled tasks that they need to complete (Dai & Wang, 2015). This thesis and the papers are in line with the process oriented perspective of family functioning (paper I-III). Several measures have been developed to assess family functioning. The two most commonly used are the Family Assessment Measure, which assesses task accomplishment, role performance, communication, affective expression, involvement, control, values, and norms (Skinner, Steinhauer, & Santa-Barbara, 2009) and the McMaster Approach to Families, which assesses problem-solving, communication, roles, affective responsiveness, affective involvement, and behaviour control (Miller, Ryan, Keitner, Bishop, & Epstein, 2000).

Other common factors that may influence the family function, according to Dai & Wang (2015), are the family structure, social and economic status, culture norms, living conditions, parent-child relationship, spousal relationship, family cohesion, age and developmental stage of the child, and life events.

The child's daily hassles, stress response, stigma and loss

According to Pedersen and Revenson (2005) the children's daily hassles, stress response, stigma and loss were, in addition to the family role redistribution, associated with the illness effects on children's well-being. Daily hassles are related to the extent that parental illness increases the difficulties associated with daily life (e.g. increased chores, nagging from parents) (Pedersen & Revenson, 2005). In this thesis, the term 'daily hassles' is defined and assessed as the nature and extent of caring activities provided by the children (paper I-III). According to the authors (2005) 'stress response' due to an 'uncontrollable' life event such as parental illness may result from illness demands associated with familial role redistribution which adversely may affect the children's peer, school, and family relationships (Pedersen & Revenson, 2005). The term 'stress response' is defined and assessed as positive and negative outcome of caregiving (Joseph, Becker, Becker, & Regel, 2009)(paper II-III), and external locus of control (paper I-III) (Nowicki & Strickland, 1973) and address the children's feeling of control of an uncontrollable life event is. The extent to which the adolescent report the parent's illness as stressful determines the children's response to the illness, including emotions, coping behaviours, or both (Pedersen & Revenson, 2005).

The CAPI model describes how family functioning is associated with the effects that parental illness has on children's well-being (Pedersen & Revenson, 2005). Several studies have found a positive association between family functioning and the children's well-being within families with parental illness or parental substance abuse (Beierlein et al., 2017; Jeppesen, Bjelland, Fossa, Loge, & Dahl, 2016; Kuhne et al., 2013; Morris, Martini, & Preen, 2016; Neger & Prinz, 2015; Pakenham & Cox, 2012b; Pedersen & Revenson, 2005; Razaz, Nourian, Marrie, Boyce, & Tremlett, 2014; Ringoot et al., 2015; Sieh, Visser-Meily, et al., 2012; Sweeney & MacBeth, 2016; van Santvoort et al., 2015; Walczak, McDonald, Patterson, Dobinson, & Allison, 2018).

1.5.2 Children's well-being

According to Seaberg (1990)the child well-being concept should be linked closely with the ability of their families to perform basic family functioning, to child protective service guidelines, moral philosophy, social indicators and quality of life, and other child well-being scales. However, the child well-being concept has previously been widely adopted within child welfare services despite lack of consensus on the meaning of the term (Seaberg, 1990). Moreover, the various ways well-being may be defined, including different domains and measures, may lead to different policies and initiatives (Seaberg, 1990; Statham & Chase, 2010). This thesis effort has been to include the emerging consensus of well-being stated by OECD (2016) and Ben-Arieh, Frønes and colleagues (2014; 2006, 2007)which understands well-being as the overall quality of people lives including many possible dimensions of people's lives. As described in the thesis section 1.3 Core concepts used in the thesis, OECD (2016) operationalised child well-being in two broad groups; 1) The well-being conditions of families where children live, and 2) Child-centred well-being factors which include their own health-status, educational and social outcomes, and QoL. A narrow QoL definition may only include dimensions of well-being that capture subjective feelings and experiences, while a broad QoL concept also include objective living conditions (Axford, Jodrell, & Hobbs, 2014; Casas, 2011; Fattore, Mason, & Watson, 2009; Holte et al., 2014).

Well-being, mental health and quality of life

The term well-being may also include mental health in terms of psychological well-being. However, mental health and QoL are different concepts, but related in several ways. Measures of mental health assess significant mental symptoms and behavioural problems, while measures of QoL address a person's subjective perceptions and experiences across several life domains (Berman, Liu,

Ullman, Jadback, & Engstrom, 2016; Jonsson et al., 2017; Matza, Swensen, Flood, Secnik, & Leidy, 2004; Sharpe et al., 2016; Steinsbekk, Jozefiak, Odegard, & Wichstrom, 2009). Quality of life measures for children provide information about the children's experiences at home and school and add important information that goes beyond symptom-focused measures. Physical and mental illness may predict an individual's QoL (Freire & Ferreira, 2016; Gaspar, Ribeiro, de Matos, Leal, & Ferreira, 2012; Jonsson et al., 2017; Raknes et al., 2017; Weber, Jud, Landolt, & Goldbeck, 2017; Zullig, Valois, & Drane, 2005; Zullig, Valois, Huebner, & Drane, 2005). However, a child with good mental health may have poor QoL and vice versa (Axford et al., 2014).
There are three well-being domains that have been addressed quantitatively in the empirical literature of CAPI: mental health in terms of problem behaviours or psychological distress, and subjective well-being in terms of self-esteem. Problem behaviours in terms of conduct problems, drug use, and other risk-taking behaviours have rarely been addressed in the research on parental physical illness (Pedersen & Revenson, 2005). Psychological distress in terms of internalising and externalising symptoms has been significantly addressed in research of physical or mental illness and substance abuse (Pedersen & Revenson, 2005). To my knowledge, subjective well-being in terms of life satisfaction has been explored more in studies of children with parental illness, such as the studies by Pakenham and colleagues on children with parents who have multiple sclerosis (2006; 2012a, 2012b). Subjective well-being is often related to QoL but is not the same idea by covering happiness, life satisfaction, and self-esteem (Axford et al., 2014; Ben-Arieh et al., 2014; Casas et al., 2008). However, there is more overlap between the concept of subjective well-being and QoL than between mental health and QoL (Axford et al., 2014).

Also more recently, quantitative research of outcomes has primarily been focused on children's psychosocial adjustment through mental health and often in terms of problem behaviour (Finan, Schulz, Gordon, & Ohannessian, 2015; Gladstone et al., 2006; Grabiak, Bender, & Puskar, 2007; Osborn, 2007; Staton-Tindall et al., 2013; Thastum et al., 2009; Visser, Huizinga, van der Graaf, Hoekstra, & Hoekstra-Weebers, 2004). However, the findings of a negative impact on emotional well-being are arguably more consistent than problem behaviour, and thereby measures of psychopathology may not sensitive be enough to assess the impact of parental illness (Backett-Milburn & Jackson, 2012; Dittrich et al., 2018; Knutsson-Medin, Edlund, & Ramklint, 2007; Osborn, 2007; Sieh, Meijer, Oort, et al., 2010; Visser et al., 2004).

Qualitative research has demonstrated that children experience several impacts from parental illness, including stigma, loss, family role redistribution, daily hassles, distress, and decreased family functioning (Backett-Milburn et al., 2008; Bogosian, Moss-Morris, Bishop, & Hadwin, 2011; Bogosian et al., 2014; Dam & Hall, 2016; Moore, McArthur, & Noble-Carr, 2011; Morley et al., 2010; Pakenham

& Cox, 2012b; P. Patterson et al., 2013; Pedersen & Revenson, 2005; Razaz et al., 2014; Sieh, Visser-Meily, et al., 2012). Such impacts may affect children's subjective well-being and quality of life (Bee et al., 2013; Jeppesen et al., 2016; Morley et al., 2010; Morris et al., 2016). A common experience reported by Norwegian children of parents with mental illness or substance abuse is that they avoid stigma, strive for normality, and undertake increased responsibility for the ill parent (Haug Fjone, Ytterhus, & Almvik, 2009; Trondsen & Tjora, 2014; Werner & Malterud, 2016). A Norwegian study of children of parents with multiple sclerosis demonstrated that the children's main concern was to preserve a feeling of control in an uncertain everyday life. They resolved this by 'balancing needs' through reflecting, adjusting, taking responsibility, and seeking respite (Mauseth & Hjalmhult, 2016). These findings have been supported in six international reviews of qualitative research (Chikhradze et al., 2017; Dam & Hall, 2016; Morris et al., 2016; Razaz et al., 2014; Rose & Cohen, 2010; Yamamoto & Keogh, 2018).

1.5.3 Illness characteristic and severity

Regardless of the type of main illness experienced by the parent, comorbid depression is the most significant factor associated with the effects that parental illness has on the children (Osborn, 2007; Pakenham & Cox, 2012b; Romer et al., 2007; Schmitt et al., 2008; Thastum et al., 2009). Meta-analysis has demonstrated increased depression and anxiety in patients with multiple sclerosis, cancer, and alcohol abuse (Boeschoten et al., 2017; Foulds, Adamson, Boden, Williman, & Mulder, 2015; Krebber et al., 2014). Systematic reviews and meta-analyses indicate associations between successful treatment of parents' depression and children's well-being (Cuijpers, Weitz, Karyotaki, Garber, & Andersson, 2015; Krebber et al., 2014; Weissman et al., 2015).

Pedersen and Revenson (2005) found that previous research had rarely studied parental illness and its impact on family functioning and children's well-being across different 'diagnoses' and 'severity'. Furthermore, the authors were questioning whether associations among parental illness characteristics, family functioning, and child well-being were similar or different across populations and contexts. According to Moore and colleagues (2011) children living with parental alcohol or drug abuse may experience more severe social exclusion, in addition to the negative impacts of their caregiving, compared to children who care for physically or mentally ill parents.

Parental illness may be characterised in greater detail by diagnosis, severity, duration and unpredictability (J. M. Patterson & Garwick, 1994; Pedersen & Revenson, 2005; Rolland, 1999). In this thesis and the included paper, the term 'diagnosis' is limited to the three types of illnesses: severe physical illness, mental illness, or substance abuse, which is in accordance with the amendment of the Health Personnel Act (Helsedirektoratet, 2010; Helsepersonelloven, 1999). The term 'severity' is in this thesis and included papers limited to the parent's self-reported health status (Ware, Kosinski, Dewey, & Gandek, 2001). The illness characteristics also include the parent's self- reported mental health by assessment of depression and anxiety (Strand, Dalgard, Tambs, & Rognerud, 2003), 'duration' in terms of years in treatment and perception of the unpredictability of the illness (paper I and III).

Different types of diagnoses may have different impacts on family life depending on factors such as prognosis and level of disability. Some diagnoses of cancer are more life threatening than others, while other types of physical illnesses such as multiple sclerosis may last longer and slowly increase the level of disability and severity. Parental mental illness and substance abuse are linked to more stigmatisation in society than physical illness (Greenwood, Mezey, & Smith, 2018; Moore et al., 2011; Östman & Kjellin, 2002). Stigma may result in other kinds of impact, such as lack of openness and less social support. More severe parental illness often impairs the parenting capacity to a greater degree and demands more from the other family members (Pedersen & Revenson, 2005; Torvik & Rognmo, 2011). The term 'parental illness characteristics' in this thesis and the papers includes the factors: type of illness, duration of illness, unpredictability of illness, physical and mental health status, and parental mental health in terms of anxiety and depression. These types of differences may lead to variations in how children are affected by parental illness. Children may also cope with parental illness differently.

1.5.4 Factors on the child and family level affected by contextual factors

Internal contextual factors

Factors on the child level (i.e. daily hassles and stress response) and family level (i.e. family role redistribution) may be affected by a number of contextual factors related to the children and family characteristics, e.g. the child and parent's age and gender, coping style, and psychological resources (Pedersen & Revenson, 2005). In this thesis and included papers we have assessed the contextual factors, i.e. children's self-reported age, gender and number of siblings. The children's coping style and psychological resources is in this thesis and included papers limited to 'social skills', and defined ' as learned socially acceptable behaviours from parents, other adults, and peers that allow a person to positively interact with others (Frey, Elliott, & Gresham, 2011; Gresham & Elliott, 2008). Moreover, the social skills are assessed as cooperation, assertion, responsibility/empathy, and self-control (Gresham & Elliott, 1990b; Humphrey et al., 2011; Ogden, 2003; Sørlie, Hagen, & Ogden, 2008).
In addition to the children's characteristics we have included the ill parent's self-reported level of family income, parental educational level and gender.

External contextual moderators

Among the potential external contextual factors Pedersen and Revenson (2005) related to parental illness and association with family functioning and children's well-being is social support and access to care. Access to external care from outside the household has been suggested to be an important moderator of the effects that parental illness may have on a child (Pedersen & Revenson, 2005). The term 'social support' is in this thesis and papers (I-III) restricted to parent's self-reported access to informal care in terms of parental social support (Cohen, 2008) and family cohesion (paper I) (Olson, 1986). The children's self-reported social support from friends will only be assessed within the concept of QoL (paper III) (Andersen et al., 2016). The term 'access to care' in this thesis and papers included is defined as access to formal external care and limited to parent's self-reported access to home-based services.

Pedersen and Revenson (2005) found no research addressing whether access to external care is associated with family role redistribution. However, they argued that there is evidence that access to external care contributes to differences in the use of health care services and health-related outcomes. They expected that greater access to high-quality care would minimise the inconvenience of treatment (reducing the extent to which families must adjust their daily routines to manage and adjust to the illness) and minimise the functional disability associated with the illness (reducing the extent to which the illness impedes the parent's ability to fulfil their role in the family). More recent reviews of the parental illness research have demonstrated that access to care may be important for the ill parent and the children (Grabiak et al., 2007; Sieh, Meijer, Oort, et al., 2010; Visser et al., 2004). Reductions of the children's caregiving and health care that focuses on parenting and family functioning can improve the child's outcomes (Neger & Prinz, 2015; Schleider et al., 2015). A review of studies on the effects of external care for patients with cancer has demonstrated that adult carers experienced increased burden of care during and after the treatment (Stenberg, Ruland, & Miaskowski, 2010). Also, Nordic studies have found that an increased burden of care on adult carers had a negative impact on the health and well-being for both the ill parent and the children (Aamotsmo & Bugge, 2014; Afzelius, Plantin, & Ostman, 2018; Alexanderson & Näsman, 2016; Birkeland, Weimand, Ruud, Hoie, & Vederhus, 2017). A systematic narrative review of European adult carers such as the spouse and adult children of patients with dementia and mental illness has demonstrated that stigma, financial difficulties, and care burdens increased their social isolation and reduced their quality of life (Greenwood et al., 2018).

Internationally, the general shift from inpatient to outpatient care has increased the number of parents who live at home while they are in active treatment (East, 2010). Deinstitutionalisation with shorter hospital stays places children in closer proximity to severely ill parents for longer periods of time (Gladstone et al., 2006; Mordoch & Hall, 2002). Also, in Norway, there has been a similar shift from inpatient to outpatient care in public hospitals, and from public hospital care to primary health care. This shift has increased the number of parents who live at home with more severe illness while they are in active treatment. Thereby, ill parents need more informal and formal external care in their own homes. However, the Norwegian home help services for periods of parental illness were established in 1960s but reduced alongside the increase of employed women and were no longer available by the late 1980s (Borgan, 2012). Since the early 1970s, the Nordic countries have the highest average increase in employed women compared to that of the other OECD countries (OECD, 2018). There has also been a decrease in families receiving home consultants and respite from the Norwegian child welfare services (Clifford & Øyen, 2018). However, the range of available home-based nursing services especially for the ill elderly has increased (Borgan, 2012). The Norwegian Directorate of Health has recognised that the shift from public hospital care to primary health care has increased the burden on the primary health care due to the increase of severely ill patients who live at home (Abelsen, Gaski, Nødland, & Stephansen, 2014; Helsedirektoratet, 2016b) and the consequence in terms of less access to external care for the severely ill patients at home (Abelsen et al., 2014; Brattheim, Hellesø, & Melby, 2016; Tønnessen, Kassah, & Tingvoll, 2016).

Qualitative studies from both Norway and the other Nordic countries have demonstrated that children with ill parents often provided increased caregiving due to a lack of informal and formal external care for their parent (Ahlstrom, Skarsater, & Danielson, 2007, 2009; Ali, Ahlstrom, Krevers, Sjostrom, & Skarsater, 2013; Bjorgvinsdottir & Halldorsdottir, 2014; Elf, Skarsater, & Krevers, 2011; Gullbrå, Smith-Sivertsen, Rortveit, Anderssen, & Hafting, 2014; Haug Fjone et al., 2009; Knutsson-Medin et al., 2007; Mauseth & Hjalmhult, 2016; Moberg, Larsen, & Brodsgaard, 2017; Pölkki, Ervast, & Huupponen, 2005; Trondsen, 2012; Östman, 2008). These findings are in line with those from other European countries and other continents (Aldridge, 2017; S. Becker, 2007; Chikhradze et al., 2017; Leu & Becker, 2016; Rose & Cohen, 2010). The lack of access to care and children's increased caregiving has been noticed in particular when a parent has physical or mental illness. Parental substance abuse and children's increased caregiving have rarely been prospectively and quantitatively explored internationally (Cox & Pakenham, 2014; Pakenham & Cox, 2015). To my knowledge, there are no Norwegian or Nordic studies which have explored children's caregiving when a parent has a substance abuse.

1.6 Young carers

This subchapter will particularly focus on research literature relevant for the selection of the independent and dependent variables related to the two first papers (I, II) of the thesis.

Young carers are children and young people who provide care for a parent or another family member with an illness due to unmet needs in the family (S. Becker, 2007). The definition of 'young carers' used in this thesis (see p. 13-14) recognises children's care for parents with any type of illness, disability or misuse of drugs or alcohol. Further, the context of caring is that the family has unmet needs, and that the children's caring may, or may not, have an adverse impact on children's health, well-being and transitions into adulthood (Cheesbrough et al., 2017; Clay et al., 2016).

The last 25 years of research of young carers has demonstrated several challenges to measure informal care among children and youth (Aldridge, 2017; Kelly, Devine, & McKnight, 2017). In the UK, there has been a challenge that the definition of young carers has changed over the years in response to the legislation on young carers support, such as the Carers Act 2014 and the Children and Families Act 2014 (Aldridge, 2017; Kelly et al., 2017). Similarly, there are several definitions of young carers in Australia, Canada, and the US (Aldridge, 2017; F. Becker & Becker, 2008; Heyman & Heyman, 2013; Kavanaugh, Stamatopoulos, Cohen, & Zhang, 2015; Leu & Becker, 2016; Smyth, Cass, & Hill, 2011; Stamatopoulos, 2015). Some definitions include young adults up to 25 years, while others use the term 'young adult carers' for the age group 16-24 years (F. Becker & Becker, 2008).

1.6.1 Prevalence of young carers

The definition of young carers used in this thesis follows the one used in the legislation of rights for carer support for those under the age of 18 years in the UK. However, this is not comparable to age categories used in surveys that have estimated the prevalence of young carers internationally. Statistics Norway uses the same age categories as other countries. Their Time Survey for 2000 and 2010 demonstrated that 1% of children aged between 9-15 years, and 2% of young adult carers aged between 16-24 years, provided care for ill, disabled, or elderly family members (Vaage, 2012). A recent Norwegian Living Condition and Health Survey from 2015 found that 2% of the population aged between 16 -24 years provided care for ill or disabled parents, half of them lived with their ill or disabled parent and half of them had left home. Unlike the Norwegian Statistics Time Survey, The Living Condition and Health Survey 2015 did not include children under the age of 16 (Isungset & Lunde, 2017; Vaage, 2012). Overall, 15% of the Norwegian population older than 16 reported that they provided unpaid care for the ill, disabled, or elderly (Statistisk Sentralbyrå, 2016). To my knowledge, the mentioned Norwegian Statistics Time Survey is the only Norwegian study of the prevalence of children under 18 years who provide caring activities for ill, disabled, or elderly parents or family members.

In a Swedish population study of young carers, a total of 7% reported a very high extent of caring activities (Nordenfors & Melander, 2017). Out of young people aged between 4-15 years, the

Scottish National Census from 2011 found 10,002 (1.5%) self-identified young carers in Scotland, and the Scottish Health Survey from 2012/2013 found 29,000 (4%) young carers (Scottish Government, 2017). These two surveys found that the prevalence rates for young adult carers, aged between 16-24 years, were 27,000 (4 %) and 64,000 (10 %) respectively. Other studies of young carers by the Scottish Government have estimated a prevalence of 7% (Scottish Government, 2017). Overall, the estimates in Europe, Australia, and the United States (US) indicate prevalence rates of young carers between 2% and 8% for children younger than 18 years (S. Becker, 2007; Kavanaugh, Stamatopoulos, et al., 2015; Leu & Becker, 2016; Nagl-Cupal, Daniel, Koller, & Mayer, 2014; Smyth et al., 2011). When the definition includes care for siblings and elderly with needs, the prevalence of young carers is much higher (Stamatopoulos, 2015). Studies of prevalence rates often use different definitions of young carers, different methods of research, different outcome measures, and samples (Aldridge, 2017; Kavanaugh, Stamatopoulos, et al., 2015; Kelly et al., 2017; Stamatopoulos, 2015). Therefore, estimates of prevalence rates and outcome are often not comparable (Aldridge, 2017; Kelly et al., 2017). Overall, studies of young carers indicate that they spent more time on caring activities than children in the general population (Nagl-Cupal et al., 2014; Pakenham et al., 2006; Warren, 2006).

1.6.2 Young carers' outcome

Pedersen and Revenson (2005) have suggested that parental illness is a negative and uncontrollable life event which may result in stress and daily hassles for the children. Daily hassles may increase when the children undertake new roles and tasks associated with the illness, such as accompanying the ill parent to medical appointments. Perceived stress may result from the demands associated with the family role redistribution (Pedersen & Revenson, 2005). Also, governmental concerns have previously been raised regarding how children who are affected by mental illness and substance abuse may provide extensive or inappropriate care for parents or siblings that may affect the children's health or development (Falch-Eriksen, 2017; NOU 2009: 8; NOU 2012: 5; Sosial- og helsedirektoratet, 2007).

Children may take on the same extent and nature of caregiving as adults, but the difference between young carers and adult carers is that children are especially vulnerable because caregiving may exceed their knowledge and developmental stage. The outcome of caregiving may be different or more severe for young carers than for adult carers (F. Becker & Becker, 2008; Cheesbrough et al., 2017; Clay et al., 2016; Smyth et al., 2011; Stamatopoulos, 2018).

Negative outcome

Two main outcomes for young carers have been examined. The first outcome is the children's subjective well-being in qualitative research, such as the individual's own experience and evaluation of their well-being in the present (Rose & Cohen, 2010). The second is the children's objective well-becoming in terms of their future personal development, transition to adulthood, and adult life (Aldridge & Becker, 2003; Axford et al., 2014; Ben-Arieh et al., 2014; Evans, 2014; Fattore, Mason, & Watson, 2006).

Previous quantitative studies of children's caring activities have found that young carers are at risk compared to their age-matched controls in terms of impact of caregiving on several significant well-being dimensions:

- Physical health (Nagl-Cupal et al., 2014; Pakenham & Cox, 2012b)
- Mental health (Cree, 2003; Pakenham & Cox, 2012a, 2012b, 2013, 2014, 2015; Shifren & Chong, 2012; Shifren, Hillman, & Rowe, 2014; Sieh, Visser-Meily, et al., 2012; Van Loon et al., 2017)
- Subjective well-being and quality of life (Kavanaugh, 2014; Lloyd, 2012; Pakenham et al., 2006; Pakenham et al., 2007; Pakenham & Cox, 2012a, 2012b, 2014; Schlarmann et al., 2008).
- School achievement and higher education (F. Becker & Becker, 2008; S. Becker & Sempik, 2018; Cheesbrough et al., 2017; Dearden & Becker, 2003; Kaiser & Schulze, 2015; Moore, 2005; Smyth et al., 2011; Stamatopoulos, 2018)

More negative outcomes (i.e. more somatisation, less life satisfaction, or more stress) have been associated with poorer parental physical health status, more than one type of illness, or if the children perceived a lack of choice in caregiving (Pakenham et al., 2006; Pakenham et al., 2007; Pakenham & Cox, 2012b, 2014, 2015).

A few studies have compared the outcomes of children's caregiving across different types of parental illness, such as severe physical illness, mental illness, or substance abuse (Cox & Pakenham, 2014; Pakenham & Cox, 2014, 2015). Two previous studies have demonstrated that children had more negative outcomes from caregiving when the parent had a mental illness than when the parent had a physical illness (Ireland & Pakenham, 2010b; Pakenham et al., 2006). However, a recent study which included the children of parents with substance abuse, found no differences in the positive or negative outcomes of children's caregiving among parental physical illness, mental illness, and substance abuse (Pakenham & Cox, 2015). The studies' findings are inconsistent.

Increased caregiving activities have been demonstrated to be associated with negative outcomes of caregiving (Pakenham & Cox, 2015, 2018). Characteristics such as the children's gender, age, ethnicity, and whether the child is in a single-parent household have been demonstrated to be largely unrelated to outcomes of caring (Pakenham et al., 2006; Pakenham et al., 2007; Pakenham & Cox, 2014, 2015, 2018; Shifren et al., 2014).

Positive outcome

In young carers research, positive outcomes of caregiving such as resilience and self-esteem are associated with the social recognition of the caregiving role and with support from friends or family (Cassidy, Giles, & McLaughlin, 2014; Nichols et al., 2013; Pakenham & Bursnall, 2006; Pakenham et al., 2006; Pakenham et al., 2007). Previous studies have also demonstrated associations between positive outcomes from children's caregiving and higher levels of social skills (Champion et al., 2009; Ireland & Pakenham, 2010b; Pakenham & Cox, 2018; van der Mijl & Vingerhoets, 2017).

1.6.3 Why do children affected by parental illness become young carers?

In the last 25 years, there has been an increase in prospective research to explore why children become caregivers (Aldridge, 2008, 2017; Aldridge & Becker, 1999, 2003; S. Becker, 2007; Evans, 2014; Evans & Becker, 2009; Smyth et al., 2011). There has been increasing publication of research papers about children's informal caregiving within the family in the UK; Australia; Canada; the US; and several European countries such as Sweden, Denmark, Iceland, Germany, Switzerland, Netherlands, and Austria (Bjorgvinsdottir & Halldorsdottir, 2014; Boumans & Dorant, 2018; Chikhradze et al., 2017; Leu & Becker, 2016; Leu, Frech, & Jung, 2018; Moberg et al., 2017; Nagl-Cupal et al., 2014; Nagl-Cupal & Hauprich, 2018; Nordenfors & Melander, 2017; Scottish Government, 2010, 2017; Sieh et al., 2013a; Sieh, Visser-Meily, et al., 2012; Smyth et al., 2011; Stamatopoulos, 2015, 2018). The reasons why CAPI become young carers have been explored within Bronfenbrenner's (1977; 1998) ecological model of children's development, which includes different system levels: the microsystem that directly impacts the child's development (family, school, and peers), the mesosystem (interconnections between the microsystems), the exosystem (parent work conditions), the macrosystem (cultural contexts), and the chronosystem (transitions over the life course and sociohistorical circumstances) (S. Becker, 2007; Evans, 2014; Evans & Becker, 2009; Jurkovic et al., 2004; Pedersen & Revenson, 2005; Smyth et al., 2011).

The young carers' paradigm places itself within the mentioned 'new' childhood sociology and emphasises children as social agents with distinct roles (e.g. James et al., 1999; Prout & James, 2003). The paradigm also holds that restrictions on the lives of children are the consequences of both these roles and the absence – or failure – of familial and external support systems (Aldridge & Becker, 1999). Within this theoretical framework, children's caregiving has been conceptualised as unpaid work or labour (S. Becker, 2007; Evans, 2014; Smyth et al., 2011). Smyth et al. (2011) has stated that care is labour embedded within a normative framework of obligation and responsibility and is also an activity which incurs costs (financial, physical, mental, and emotional). Becker (2007, p. 24) has argued that;

> Recognising children's caring activities as work is to politicise and to make public the activities, roles, value and outcomes that characterise unpaid and family-hidden caregiving, and to identify these issues as concerns for social and public policy and for social development.

The rationale for this is that when parents are ill, their needs may not be met by the primary health care services or the public hospitals. The result may be that the children of these parents must engage in distinct caring activities such as personal or intimate care which home-based services normally provide and which are not required of the children of healthy parents (S. Becker, 2007). On the community level, it is the access to formal and informal external care that influences whether children take on caring roles and which may increase the extent and nature of the caring activities. On a micro level, Evans and Becker (2009) have pointed out that factors such as the family member's health status or impairment, low income, co-residence, relationship to the parent or family member in need of care, and the children's personal attributes may significantly influence the extent and nature of caring activities and the outcome of caregiving.

The conceptualisation of children's caregiving as unpaid work was supported by the Children's Ombudsman in Norway (Hjermann, 2007). He encouraged examining a broad spectrum of factors to understand why children become carers in Norway.

Recent international research has included children as sources in the study of young carers. A meta-synthesis of qualitative studies has indicated that young carers felt that they had no choice in adopting a caring role (Rose & Cohen, 2010). While they defended their caregiving with 'This is my family, and I am a carer because I love my family', they also wanted their efforts to be recognised, and for support that was 'good enough' to be provided for the family (Rose & Cohen, 2010).

1.6.4 Changes in perspectives on children's caregiving in research of parentification – from pathological to learned normative behaviour

The concept of parentification from the 1960s was established by central family theorists such as Munichin (1967), Bozormenyi-Nagy and colleagues (1986; 1973), and Bowlby (1977). Within parentification, children's caregiving can be categorised into emotional caregiving, which involves taking care of the parent's emotional needs or burdens; and instrumental caregiving, such as cleaning, washing the dishes, preparing meals, or watching siblings (Champion et al., 2009). The central theorists within family theory have suggested that emotional responsibility is the core of the parentification process and can have a destructive impact on the child's development (attachment, security, trust in adults and self-esteem) (Haxhe, 2016).

At the same time, another central parentification theorist, Jurkovic (1997), has presented a model of caregiving characteristics that includes length, intensity, degree of responsibility, type of care, the context of care, and the different consequences of the caregiving. The model is useful because it includes various contexts for children's caregiving; these contexts range from illness and substance abuse to any other reason for the absence of a parent (Chase, 1999; Haugland, 2006; Winton, 2003). One example of parental absence is the Norwegian study by Haugen (2007) which explored caring children in post-divorce families. The study describes the complex relations between caregiving and care-receiving among children and adults, which challenge and nuance the traditional western picture that emphasizes children as the receivers of care and adults as care-givers. To my knowledge this is one of two Norwegian studies of children's caring explored within the perspective of 'new sociology of childhood'. The other study by Nilsen & Wærdahl (2015), explored extent of children's work at home, gender differences and whether these were correlated with the parents' socialization goals, work status and level of education. This study indicated gender differences in extent of work at home and gender bias in how children perceive expectations of work and participation at home and suggest that the variations more likely derived from a generalised socially constructed image of what mothers and fathers do. In line with Gresham and Eliot (2008), level of pro-social behaviour in terms of caregiving may be learned behaviour.

At one end of the continuum, Jurkovic (1997) has described 'destructive parentification', which includes extreme caregiving for one or both parents over an extended period of time where the expectations for the child are not age-appropriate and the child receives no credit, appreciation, or acknowledgments by the parents or others for the efforts that the child provides (Earley & Cushway, 2002; Winton, 2003). Boszormenyi-Nagy and colleagues (1986; 1973) have associated destructive parentification with the absence of reciprocity, acknowledgment, and support within the family (Jurkovic et al., 2004). Jurkovic's (2004) examples are when a child prevents a parent from drinking alcohol or using drugs, or when a child attempts to ensure that a mentally ill parent maintains stability by taking their medication.

The other end of the continuum has been described by Jurkovic as 'adaptive parentification', which can be a consequence of family crisis or acute stresses where the caregiving may be long-term, but the provision of care is recognised and appreciated by the family or community. Some examples include when a child becomes the caretaker of parents who are wounded or in pain, when a child replaces a parent who becomes physically or mentally ill, or when a parent leaves the family.

Jurkovic and colleagues (2004) have subsequently introduced the term ‘filial responsibility’, which describes children providing instrumental and emotional assistance to their families. He has recommended that this term should replace the term ‘parentification’ to avoid pathological and ethnocentric connotations because extensive caregiving by children is normative in times of crisis such as illness and is also recognised and supported in many cultures (Godsall, Jurkovic, Emshoff, Anderson, & Stanwyck, 2004). Elsenbroich & Xenitidou (2012) define ‘normative behaviour’ as a result of a normative decision, where the decision is normative if it is brought about by (direct or indirect) social influence. Helping parents is a valuable process for learning and socialising and likely to be motivated by adult members in the family (Bruckauf & Rees, 2017). Jurkovic and Casey (2004) developed the Filial Responsibility Scale based on Bronfenbrenner’s (1977; 1998) ‘ecology of human development’, as a result of their changes in perspectives on children’s caregiving from pathological to normative behaviour. This means that they in line with other researchers look at caregiving as a good social skill learned from parents and others that allow a person to positively interact with others (Frey et al., 2011; Gresham & Elliott, 2008).

1.6.5 Levels of children’s caregiving

Becker (2007) has conceptualised children’s levels of caregiving on a continuum from ‘caring about’ to ‘caring for’ a family member. To care about a family member is common and implies that the provided care is at a lower level, less direct, and may be performed at distance. To care for a family member is less common and implies that the care is at a more advanced level, is performed directly, and is provided through everyday practice. The continuum is helpful for highlighting the different levels of caregiving. The majority of children are more involved in ‘caring about’ and less in ‘caring for’. This balance may shift over a period of parental illness, and a small proportion of children may become involved in significantly more demanding caregiving for family members with illness, disability, or substance abuse (Evans, 2014). The caregiving and responsibility shouldered by the children may increase and decrease in amount, regularity, complexity, intimacy, hours spent per week, and overall duration.

The degree to which children provide care in the family may also be hidden from the public because it is not considered culturally appropriate for children to do so across the generations (Aeyelts, Marshall, Charles, & Young, 2016; S. Becker, 2007; Evans, 2010). Parental reluctance to identify children as a carer may be due to the fear of the involvement of child protection services and stigma (Aldridge, 2006). The young carers may fear stigma and choose to hide the level of their caregiving from others because being a young carer challenges the notion that adults are the care providers and young people are the recipients of care (McDougall, O'Connor, & Howell, 2018; Smyth, Blaxland, & Cass, 2010). The family’s concealment of the children’s provision of care because they are afraid of any child protection involvement is particularly pertinent in cases of mental illness and substance abuse (Aeyelts et al., 2016; Aldridge, 2006; Järkestig-Berggren, Bergman, Eriksson, & Priebe, 2018; McDougall et al., 2018).

1.6.6 Factors related to the well-being conditions of families where children live

Several factors have been demonstrated to be associated with the extent of caregiving provided by children, particularly factors related to the well-being conditions of families where children live, such as family socio-demographics, parental illness characteristics and severity, and access to informal and formal external care.

Family socio-demographic variables – Children provide more caring activities for mothers with illness compared to fathers with illness (F. Becker & Becker, 2008; Dearden & Becker, 2004; Ireland & Pakenham, 2010a; Nagl-Cupal et al., 2014; Sieh et al., 2013a). Older children reported higher extent of caring activities, specifically domestic and personal care, than younger children (F. Becker & Becker, 2008; Ireland & Pakenham, 2010a). Low family income and single-parent households have been found to be associated with higher extent of caring activities (S. Becker, 2007; Ireland & Pakenham, 2010a; Kavanaugh, 2014; Nagl-Cupal et al., 2014; Pakenham & Cox, 2014, 2015; Smyth et al., 2011); however, one of the studies did not find this for single-parent households (Nagl-Cupal et al., 2014), and another study found no association between demographics and caregiving (Bauman et al., 2006).

Parental illness characteristics and severity - Some types of illness, greater severity of the illness, and longer duration of the illness have been associated with higher extent of children's caring activities (Ireland & Pakenham, 2010b; Pakenham & Cox, 2012b, 2015). Children provided more caring activities to parents with physical illness than to parents with mental illness (Dearden & Becker, 2004; Ireland & Pakenham, 2010a), and even more when combined (Ireland & Pakenham, 2010a). Providing personal care was more common to parents with severe physical illness (Bjorgvinsdottir & Halldorsdottir, 2014; Kavanaugh, 2014) than to parents with severe mental illness (Dearden & Becker, 2004; Ireland & Pakenham, 2010a). One recent study found no differences in the extent and nature of children's caring activities between physical illness, mental illness, and substance abuse (Pakenham & Cox, 2015).

Access to informal and formal external care - Lack of access to formal care such as home-based services or informal care within the family or network have been associated with more care from children (Aldridge & Becker, 1999; F. Becker & Becker, 2008; Bjorgvinsdottir & Halldorsdottir, 2014; Dam & Hall, 2016; Heyman & Heyman, 2013; Moore & McArthur, 2007; Nicholls, Patterson, McDonald, & Hulbert-Williams, 2017; Nichols et al., 2013; Pakenham & Cox, 2012b, 2015; Rose &

Cohen, 2010; Sieh, Meijer, & Visser-Meily, 2010; Sieh et al., 2013a; Smyth et al., 2011; Svanberg, Stott, & Spector, 2010). Essentially, children have been found to provide care when there are no other alternatives (Leu & Becker, 2016; Metzing-Blau & Schnepp, 2008; Smyth et al., 2011).

1.6.7 Child-centred well-being factors associated with children's caregiving

The concepts of parentification and young carers recognise the significance of reduced parental capacity due to parental illness, disability, or substance abuse in the family. Recently, prospective and retrospective studies of parentification have been published, which may add relevant new knowledge to the field. These studies found that children's emotional and instrumental caregiving are related to social skills and the feeling of control.

Children's caregiving and social skills

One previous study has demonstrated that emotional caregiving, for mothers with and without a history of depression, was a unique predictor of children's social skills, while instrumental caregiving was not (Champion et al., 2009). Two studies of children with parents with the human immunodeficiency virus (HIV) demonstrated that the more adult responsibilities shouldered by the children, the higher their levels of reported social skills (Stein, Rotheram-Borus, & Lester, 2007; Tompkins, 2006). A recent study demonstrated a positive association between parentification in terms of emotional caregiving and empathy, and no association between instrumental caregiving and empathy (van der Mijl & Vingerhoets, 2017). However, it remains unclear whether the children's social skills and empathy were a result of the emotional caregiving for a parent, or whether the emotional caregiving for a parent was a result of social skills and empathy. The motivation for helping is that prosocial behaviour, which is defined as helpful behaviour or acts that are undertaken to protect or enhance the welfare of others, such as friends and looking out for parents are associated with the well-being of the helper (Fattore, Mason, & Watson, 2016; Holte et al., 2014; Spinrad & Eisenberg, 2017).

Children's caregiving and their feeling of control

As mentioned, Pedersen and Revenson (2005) have indicated that parental illness may be an uncontrollable life event. The parental illness may be experienced as a threat and create feelings like helplessness and worry about parental death, children's worry about their own health, and family-level perceived stigma. Further, the result may be an increase in the children's caregiving. Individuals, who feel in control of the situation and what happens, feel the internal locus of control, while individuals who do not feel in such control feel the external locus of control (Galvin, Randel, Collins, & Johnson, 2018). This feeling relates to how the children believe they can control their life, the events affecting themselves, and where that control comes from (Kaura & Sharma, 2015). The necessary skills are required to master and control events. A retrospective study of the relationship between parentification and locus of control has indicated that the internal locus of control negatively moderated the association between childhood parentification and childhood depression (Williams & Francis, 2010). Another retrospective quantitative study of parental alcoholism and parentification of children has demonstrated that the children's caregiving endowed them with a sense of control in an otherwise uncontrollable situation (Burnett, Jones, Bliwise, & Ross, 2006).

1.6.8 Measurements of children's caring activities

Within research of children's help and care for the family, particular parental illness, young carers and parentification there has been developed different methods and validated measures to assess children's caring activities (Armstrong-Carter, Olson, & Telzer, 2019). The Youth Activities of Caregiving Scale (YACS) was developed by Ireland and Pakenham (2010a) and includes the subscales: instrumental care, personal/intimate care, domestic/household care and social/emotional care. The social/emotional care subscale include items such as "Keeping them happy, company, occupied, safe", "Helping them when they feel bad, when they are tired" and "Walking with my family member". The other method is the 'Multidimensional Assessment of Caring Activities Checklist' (MACA) developed by Joseph and Becker (2009). MACA is filled out by the children themselves. There is one version with 42 items (MACA-YC42) and a shorter version with 18 items (MACA-YC18). The shorter version has six subscales: domestic, household, financial and practical management, personal care, sibling care and emotional care. The emotional subscale includes the items "Keep the person you care for with company e.g. sitting with them, reading- or talking to them", "Keep an eye on the person you care for to make sure they are alright", and "Take the person you care for out, e.g. for a walk to see friend or family". Two other questionnaires were also developed which were not validated. One was developed in Austria by Nagl-Cuple and colleagues (2014). However, this questionnaire is not available online. The other is the 'YC-QST-20 (Mental health) Young Carers: Questionnaire and Screening Tool', which was developed in the UK by the Young Carers Research Group on behalf of the Department of Education to explore the prevalence, characteristics, and circumstance of young carers and the impact of caregiving on their lives (Cheesbrough et al., 2017; Young Carers Research Group). This questionnaire has one item of emotional care as follows; "Do you provide any emotional help to your relative, such as sitting with them, trying to make them laugh, cheer them up, talking to them about their problems". Other measures are the Filial Responsibility Scale developed by Jurkovic and Casey (2004) and the Parentification Questionnaire – Youth (PQ-Y) (Godsall et al., 2004), which to my know-ledge have not been used, except for one study by Van Loon and colleagues (2017) with the PQ-Y.

In this thesis, we used all the items from MACA-YC18 and three items (the health care subscale) from the MACA-YC42 to collect children's self-reports of common caring activities at home when an ill parent needed care (Joseph et al., 2009). These data will from now on be referred to as the MACA. The use of the term and the definition of emotional care is in line with the items in the emotional subscale of the MACA-YC18, which are: keeping the parents company, keep an eye on the person you care for to make sure they are alright, or help them out to see others, family or friends. The MACA was chosen because it was developed within a European context and validated to assess children's caring activities in samples with different types of parental illnesses. At the time of the selection of measurements for the study, the MACA was one out of only two available validated instruments. The items in the MACA are similar to questions in Statistics Norway's Living Condition and Health Survey 2015. They measured the extent and nature of unpaid care for the ill, disabled, or elderly in the general population provided by young adult carers over 16 years of age (Helsedirektoratet, 2018; Isungset & Lunde, 2017).

1.6.9 Measurements of the outcomes of children's caring activities

Despite the increase in cross-sectional outcome studies, research on the positive and negative outcomes of children's caring activities may have been hampered by the lack of contextually sensitive measures (Aldridge, 2017; Cox & Pakenham, 2014; Joseph et al., 2009; Leu & Becker, 2016; Pakenham et al., 2007; Pakenham & Cox, 2012b, 2018). Three context-sensitive measures filled in by the young carers have recently been developed. These three measures focus on both positive and negative outcomes (Cassidy & Giles, 2013; Cox & Pakenham, 2014; Joseph et al., 2009; Pakenham & Cox, 2018). The Perceived Impact of Child Care-giving Scale (Cassidy & Giles, 2013) is a 22-item scale developed from the Young Carer Perceived Stress Scale (YCPSS) and focuses on benefits and stress (Early, Cushway, & Cassidy, 2006). The Young Carer of Parents Inventory (YCOPI) (Pakenham et al., 2006) has two parts. The YCOPI-A assesses caregiving experiences that are applicable to all caregiving contexts, while the YCOPI-B assesses dimensions related to youth caregiving in the context of parent illness. According to Cox and Pakenham (2014), the YCOPI can be used for valid comparisons between the youth of a parent with a significant medical condition and their peers with 'healthy' parents. The authors of the YCOPI state that young carers and children of 'healthy' parents conceive of caregiving and outcome in very similar ways. There are also two questionnaires that assess the outcomes of parental physical illness and the extent of increased caring activities (Bogosian et al., 2014; Morley et al., 2010), which will be described more thoroughly in the section on children's quality of life (see 1.7.5).

In this thesis, we used the Positive and Negative Outcomes of Caring Scales (PANOC-YC20) (Joseph et al., 2009) to assess the consequences of the children's care for ill parents. The PANOC-YC20 scale assesses the positive and negative cognitive and emotional effects of caregiving (Joseph et al., 2009). At the time of the selection of the instrument for this thesis, the PANOC-YC20 and the YCOPI scale of Pakenham and Bursnall (2006) were the only validated instruments. The PANOC-YC20 will from now on be referred to as PANOC.

1.7 Children's quality of life

This subchapter will particularly have a focus on research literature relevant for the selection of the independent and dependent variables related to the third paper (III) of the thesis.

Studies of QoL are mainly explored by generic instruments based on different conceptual and theoretical perspectives. In the following sections, I will describe the relevance of QoL overall and QOL for children in general, CAPI, and young carers.

1.7.1 The relevance of quality of life

There has been increased focus on the importance of assessing the QoL of CAPI and young carers (Bee et al., 2013; Morley et al., 2010; Schlarmann et al., 2008; Weber et al., 2017). The Norwegian Directorate of Health (Nes, Hansen, & Barstad, 2018) has defined subjective QoL on three dimensions: level of satisfaction with life in general and in specific areas (cognitive), positive feelings such as happiness and joy as well as negative feelings such as anger and nervousness (affective), and psychological functioning and satisfaction of needs (eudaimonia). Children's QoL may be affected by contextual burdens such as illness, either suffered by siblings, parents, or the children themselves (Berman et al., 2016; Dittrich et al., 2018; Jonsson et al., 2017).

However, measuring and monitoring the QoL of children is important for multiple reasons. Assessing children's QoL may serve as an early indicator of psychosocial problems, indicate needs, and add significant information not detected by assessments of psychosocial adjustment (Bisegger et al., 2005; Jonsson et al., 2017; Jozefiak, Larsson, Wichstrom, Wallander, & Mattejat, 2010; Meade & Dowswell, 2016; Ravens-Sieberer et al., 2007; Vella, Magee, & Cliff, 2015). Furthermore, the concepts of children's rights and children's QoL are closely connected. The United Nations Convention on the Rights of the Child (UNCRC) has underlined that children's QoL is important, and QoL is mentioned in several of the UNCRC's articles. Children are more vulnerable than adults because they are developing and are dependent on parental and adult support. Finally, children's QoL could be examined for signs of improvement or deterioration in response to changes (Axford et al., 2014; Ben-Arieh & Frønes, 2007; Casas, 2011; Kosher & Ben-Arieh, 2017; Wallander & Koot, 2016).

1.7.2 Development of different concepts of quality of life and measurement

Research of children's QoL is a recent field and has grown over the past decade but is still underexplored compared to adult QoL research (Huebner et al., 2004; Jonsson et al., 2017; Ravens-Sieberer et al., 2001; Wallander & Koot, 2016; Wallander, Schmitt, & Koot, 2001). QoL is defined in several ways and may be different for adults and children because the factors that affect children's QoL may be different from those that affect the QoL of adults (Casas, 2011; Huebner et al., 2004; Jonsson et al., 2017; Matza et al., 2004). The development of QoL research for children has been about a decade later than the research of adult QoL and has occurred in three waves, health-related quality of life (HRQoL), social indicators, and subjective well-being. In the following section, I will describe the main concepts more thoroughly.

Health-related quality of life

HRQoL has become the most frequently used approach to assess children's QoL in epidemiological and clinical health research and has dominated the consideration of QoL in children and adults (Holte et al., 2014; Wallander & Koot, 2016). HRQoL is a narrow multidimensional construct that covers the physical, mental, and social domains of health, and is developed to assess an individual's subjective experience of health, disease, disability, impairment, and the effects of medical treatment (Ravens-Sieberer et al., 2006; Seid, Varni, & Jacobs, 2000; Solans et al., 2008; Wallander & Koot, 2016). This concept has often been used to measure the status of patient populations, typically as an outcome of medical activity and as compared to the general population (Varni, Burwinkle, & Seid, 2006; Wallander & Koot, 2016). As an approach to understand QoL in children, HRQoL has limitations. While health is an important aspect of QoL, it is not synonymous with QoL. Hence, self-reported good health may occur alongside low well-being scores and self-reported poor health may occur alongside high well-being scores (Holte et al., 2014; Wallander & Koot, 2016).

One of the most well-established instruments is the Pediatric Quality of Life Inventory, which assesses domain-specific and global HRQoL on four domains: physical, emotional, social, and school (PedsQL) (Varni et al., 2006). Another well-established instrument is KIDSCREEN (Ravens-Sieberer et al., 2001; Ravens-Sieberer, Herdman, et al., 2014), which was simultaneously developed in 13 European countries, translated to at least 38 languages, and exists in both self-reported and proxy-reported versions of different lengths. For example, KIDSCREEN-27 covers five domains: 1) physical well-being, 2) psychological well-being, 3) parent relations and autonomy, 4) social support and peers, and 5) school. It addresses both the negative and positive aspects of life in the past week. Most of the other HRQoL measures address the negative aspects only (Ravens-Sieberer et al., 2007; Wallander & Koot, 2016). According to Wallander and Koot (2016), the broad distribution of domains makes KIDSCREEN a broader measure of QoL than HRQoL.

Social indicators

The second concept of QoL is social indicators, which address the common domains of wealth and material well-being, housing and living environment, education, health and safety, risk behaviours, and legal status. Child social indicators are commonly population based and are mainly used to reflect the QoL of a demographic group of children rather than to measure individuals (Wallander & Koot, 2016). Social indicators have several strengths: they are easily defined and quantified, reflect the normative ideals of a society, and are more objective (Diener & Suh, 1997; Wallander & Koot, 2016). Most social indicators reflect problems or negative outcomes instead of positive outcomes (Wallander & Koot, 2016). One issue with social indicators is whether objective measures adequately depict children's QoL (Wallander & Koot, 2016). Most definitions of QoL imply that it is a subjective experience and are consistent with the UNCRC, which says that children's views should be considered when deciding matters that affect them (Wallander & Koot, 2016). There have been essential contributions to develop social indicators of children's subjective well-being: the 'new' childhood sociology (Christensen & James, 2008), the ecology of child development (Bronfenbrenner & Morris, 1998), the recognition of children's rights, and initiatives to improve policy decisions by collecting information about various areas of the lives of children and adolescents (Casas, 2011; Fattore, Mason, & Watson, 2012).

Subjective well-being

Subjective well-being measures were intended to add to, but not replace objective social indicators. Subjective well-being is a multidimensional and positively oriented concept that encompasses how well life is going for a person (Cummins, 2010; Ravens-Sieberer, Herdman, et al., 2014). Subjective well-being is essentially similar to perceived QoL (Huebner, Gilman, & Ma, 2012), psychological well-being (Gonzalez, Casas, & Coenders, 2007), and subjective QoL (Cummins, 2000). A primary strength of using subjective well-being to understand QoL is that it enables children to appraise their own personal QoL with the full range from negative to positive well-being. This enables reports to be sensitive to changes above and below the neutral point (Holte et al., 2014; Wallander & Koot, 2016). High QoL cannot be attributed merely to the absence of problems but must incorporate degrees of positive experience such as happiness, satisfaction, and meaning to capture the full range of well-being and indicate the quality of people's lives.

Multidimensional measures of subjective well-being can reveal which life circumstances are more important to how young people experience the quality of their lives and can take individual values and preferences into account (Wallander & Koot, 2016). These measures can provide information about individuals and groups to the public and policymakers. On the negative side, there remains a conflict whether subjective well-being should include the global perspective only, or whether satisfaction with or happiness in specific domains matters. Measuring subjective well-being globally and in specific domains should be advantageous to build the knowledge base about subjective well-being in childhood. Research on subjective well-being in children is severely underdeveloped in comparison with the research on adult subjective well-being (Wallander & Koot, 2016).

One of the most commonly used measures is the Brief Multidimensional Students' Life Satisfaction Scale, which assesses family life, friendship, school experiences, self, and the living environment (Seligson, Huebner, & Valois, 2003). Another relevant questionnaire assesses the subjective well-being measures, which determines positive affect, life satisfaction, meaning, and purpose (Ravens-Sieberer, Devine, et al., 2014).

Wallander and Koot (2016) have conducted a critical examination of the concepts, approaches, issues, and future directions of QoL in children. The authors have concluded that social indicators and subjective well-being best capture the children's QoL by providing information on objective and subjective QoL. On the other hand, HRQoL is an inadequate concept of QoL due to its limited dimensions and its focus on ill-being rather than well-being.

Factors associated with children's QoL in the general population

In the general population, lower QoL for children is associated with parental socioeconomic factors, such as lower levels of parental education, low family income (Bradshaw, Keung, Rees, & Goswami, 2011; Ravens-Sieberer, Herdman, et al., 2014; Ravens-Sieberer et al., 2013; Vella et al., 2015; von Rueden, Gosch, Rajmil, Bisegger, & Ravens-Sieberer, 2006), and single-parent family status (Berman et al., 2016; Bradshaw et al., 2011; Kvarme, Haraldstad, Helseth, Sorum, & Natvig, 2009). Proper family functioning is also positively associated with children's QoL in the general population (Jozefiak & Wallander, 2016). The level of QoL often changes over time and decreases from childhood to adolescence (Berman et al., 2016; Jozefiak, Larsson, & Wichstrom, 2009; Meade & Dowswell, 2016). Furthermore, children's QoL is worse for girls than boys, and worsen with increasing age (Bisegger et al., 2005; Bradshaw et al., 2011; Meade & Dowswell, 2016; Ravens-Sieberer et al., 2007). Other factors that are positively associated with QoL include the personal characteristics of the child such as locus of control, self-esteem, social skills, and optimism, as well as social factors such as social support (Detmar et al., 2006; Gaspar et al., 2012). Some studies have demonstrated that unmet needs such as limited access to health services are associated with lower QoL (Morley, Selai, Schrag, Jahanshahi, & Thompson, 2011; Nicholls et al., 2017; The KIDSCREEN Group Europe, 2006).

1.7.3 Qualitative studies of children's subjective well-being

A review of qualitative methods to explore the concepts and experiences of well-being among children has proposed that qualitative approaches are essential for understanding experiences of subjective well-being and has recommended combining data from qualitative and quantitative approaches to enhance explanatory power (Camfield, Crivello, & Woodhead, 2009). There are two qualitative studies that are of particular relevance for the papers included in the thesis.

A focus group study of children between 8-18 years in six European countries found that the most important aspect of QoL for young children was family and social functioning (Detmar et al., 2006). Family functioning included the relationship and interactions with parents and atmosphere at home. Social functioning included positive and negative peer encounters (playing or bullying) and relationships (Detmar et al., 2006). Social functioning was the most important factor for younger and older adolescents. Physical and cognitive functioning was less important than family and social functioning. These key findings were considered when designing the KIDSCREEN QoL questionnaire for healthy children and adolescents (Detmar et al., 2006). A study by Fattore and colleagues (2009) found that the most important factors for the children's subjective well-being were:

Positive sense of self refers to the children's emotional life and relationships.

Social responsibility refers to the feeling of being a good person when the children helped friends, did well at school, and looked out for parents. Some examples of interactions which shaped the children's sense of being a good person included helping out by doing one's share, supporting and caring for family members, and trying to meet the parent's expectations of how to act by treating others fairly and with honesty.

Control of everyday life refers to the children's access to control and mastery of everyday life, including the involvement in and influence on formal decisions that are relevant to them at home and at school.

Security and safety refer to the feeling of having protecting parents, of having a safe place to return to, and having people they can trust will be around them.

1.7.4 Quantitative research of quality of life in children affected by parental illness

There has been an increase in studies that have quantitatively assessed generic QoL in children affected by parental illness or substance abuse (Bee et al., 2013; Comiskey et al., 2017; Krattenmacher et al., 2013; Kuhne et al., 2012; Morley et al., 2011; Sieh, Meijer, & Visser-Meily, 2010; Weber et al., 2017). I found 19 relevant studies from 2006 to 2017. Most were related to parental cancer, and a few were related to parental mental illness. Four quantitative studies indicated no association between parental cancer and children's QoL (Bultmann et al., 2014; Jeppesen et al., 2016; Krattenmacher et al., 2013; Kuhne et al., 2012). One Norwegian study found lower QoL for the children of parents with cancer compared to a control group (Hauken, Pereira, &

Senneseth, 2018), while another Norwegian study found no differences except for lower QoL in the physical well-being dimension compared to European norm data (Jeppesen et al., 2016). Two qualitative studies found lower QoL in the children of parents with chronic conditions or cancer (Helseth, Lund, & Christophersen, 2006; Nicholls et al., 2017). Research on young carers and their QoL is mostly qualitative. A few quantitative studies have used validated questionnaires and have demonstrated lower life satisfaction, poorer QoL, and health in young carers compared to young non-carers (Chikhradze et al., 2017; Fraser & Pakenham, 2009; Lloyd, 2012; Pakenham et al., 2006; Pakenham & Cox, 2012a).

Overall, some of the research literature has demonstrated that children and young carers affected by parental illness are at risk for reduced well-being and QoL (Chikhradze et al., 2017; Coker et al., 2011; Dittrich et al., 2018; Giannakopoulos et al., 2009; Jeppesen et al., 2016; Leu et al., 2018; Lloyd, 2012). However, these findings were inconsistent.

1.7.5 Measurement of quality of life in children affected by parental illness

To my knowledge, there are two measures that have been developed to assess the QoL of children affected by parental illness. The Parental Impact Scale is a questionnaire that was developed to measure the QoL of children of neurotically affected parents (Morley et al., 2010). The Perception of Parental Illness questionnaire has been developed to measure the QoL of the children of parents with multiple sclerosis (Bogosian et al., 2014). Both of them include positive and negative consequences for the various dimensions of impacts, such as increased practical and emotional care for the parent, unpredictability, feeling a lack of control, and emotional stress.

One measure assesses the unmet needs of children who have a parent with cancer. This includes the need for information, support and open communication with their family, assistance for the ill parent and the household, access to supportive services, respite and recreation, dealing with feelings, and supportive peers (P. Patterson et al., 2013). More recently, the ‘Offspring Chronic Illness Needs Inventory (OCINI) was developed, which measures unmet needs in young adults with a parent with a chronic physical condition (Nicholls et al., 2017). The development study by Nicholls and colleagues (2017) has found positive correlations between unmet needs and stress, anxiety, and depression, which indicate an inverse relationship between unmet needs and QoL.

1.7.6 Predictive model of factors associated with quality of life for CAPI

Generic instruments allow us to compare CAPI with the general population. However, generic QoL instruments may fail to capture specific areas of importance for children affected by parental illness. I have therefore chosen to explore the extent and nature of the children’s caring as well as their outcomes regarding well-being and quality of life. I have chosen to use the KIDSCREEN (Ravens-

Sieberer, Herdman, et al., 2014) because of its broader concept of QoL and its assessment of the negative and positive aspects of life. These aspects are not featured in other QoL measures (Ravens-Sieberer, Herdman, et al., 2014; Wallander & Koot, 2016). The CAPI model developed by Pedersen & Revenson (2005), previous research on young carers and research of QoL have been important for choosing factors hypothesized to be associated with the QoL of CAPI. The selection of factors were also inspired by the OECD (2016) operationalisation of child-well-being, and is as follows:

1) The well-being conditions of families where children live:

- Family socio-demographics (i.e. gender, level of education, level of family income, single-parent family versus two parent family)
- Parental illness characteristics and severity (i.e. illness duration, predictability, health status [SF-8], mental health [SCL-10])
- Family functioning (i.e. family cohesion [FACES III], parental capacity)
- Parental access to care (i.e. home-based services) and social support [ISEL-12]

2) Child-centred well-being factors:

- Children's characteristics (age, gender, social skills [SSRS])
- Family role redistribution (i.e. increase in responsibilities and other adults take over responsibilities for the ill parent)
- Daily hassles (i.e. nature of caregiving [MACA])
- Child stress response (i.e. outcome of caregiving [PANOC] and Locus of Control).

1.8 Children affected by parental illness in Norwegian context

This section describes the prevalence of CAPI in Norway and national gaps of research knowledge.

The Norwegian Health Care Act amendment covered the children of parents with severe physical illness, mental illness, and substance abuse (Helsepersonelloven, 1999). However, there is little previous research investigating the outcomes for CAPI across different types of parental illnesses (Krattenmacher et al., 2014; Pakenham & Cox, 2014; J. M. Patterson & Garwick, 1994; Pedersen & Revenson, 2005; Rolland, 1999). The Norwegian Directorate of Health (2016a), points out that a weakness in existing studies is lack of national data that includes information provided by children under 16, particularly including subjective QoL, and limited research on how to promote mental health and subjective well-being.

Prevalence of children affected by parental illness in Norway

On the 1st of January 2013, the year we recruited participants for the study, there were 1.230 million (22%) children under the age of 18 years in Norway. Out of these, 0.625 million were aged between 8-17 years (Statistisk Sentralbyrå, 2013). Many children have an ill parent. The ill parent had a mental illness more often than a physical illness or a substance abuse problem. The Norwegian Institute of Public Health estimated in 2011 that between 12% and 40% of children younger than 18 had a parent with mental illness or alcohol abuse issues (Torvik & Rognmo, 2011). The highest number (40%) included parents with mild, moderate, or severe disorders, and the lowest number (12%) included parents with a severe disorder only. The authors found that a relatively moderate to severe parental mental illness or alcohol abuse often leads to reduced care or negative outcomes for the children. In 2011 in Norway, there were an estimated 260,000 children (23.1%) who had a parent with a moderate to severe mental disorder, an estimated 70,000 children (6.5%) who had a parent with alcohol abuse issues that most likely affected the parent's daily functioning, and an estimated 290,000 (26.5%) children who had a parent with both these disorders (Torvik & Rognmo, 2011). An estimated 115,000 (10.4%) children had a parent with a severe mental illness and an estimated 30,000 children (2.7%) had a parent with severe alcohol abuse. In total, 135,000 children (12.2%) were in both groups.

Several studies in Norway have estimated the number of children who live with a parent with cancer and multiple sclerosis, which are the two largest groups of severe physical illness among parents. In 2007, there were an estimated 3,481 (0.3%) children under 18 who had a parent diagnosed with cancer with a mean age of 8 years (Syse, Aas, & Loge, 2012). Approximately 4% of children aged 0–25 had or still have parents diagnosed with cancer, which corresponds to a population prevalence of 1.4%, while around 20% of these children experienced parental death (Syse et al., 2012). Multiple sclerosis prevalence in Norway is among the highest worldwide, and an estimated 10,000 children (0.9 %) aged 0-17 have a parent diagnosed with multiple sclerosis (Berg-Hansen, Moen, Harbo, & Celius, 2014; Mauseth & Hjalmhult, 2016).

Lack of research of young carers in Norway

Prior to the Health Personnel Act amendment in 2010 (1999), the Norwegian Directorate of Health and The Ministry of Health and Care Services have expressed concerns that children who care for a parent with severe illness or substance abuse were at risk for more mental health problems and suggested that the families could benefit from home-based services, including practical help (Helse- og omsorgsdepartementet, 2009; Helsedirektoratet, 2010; Sosial- og helsedirektoratet, 2007). In 1999, at the same time, other countries, especially UK and Australia, were 20 years ahead regarding research on the situation for young carers that also included the children as sources. In addition, they had investigated which interventions and measures may provide effective help. These nations had developed national policies and legal legislation based on this research (Aldridge, 2017; S. Becker, 2007; Leu & Becker, 2016; Smyth et al., 2011). However, only a few previous studies have explored differences in children's caregiving across different types of illnesses such as physical illness, mental illness, and substance abuse (Cox & Pakenham, 2014; Dearden & Becker, 2004; Ireland & Pakenham, 2010b; Pakenham et al., 2006), and there is only one study that has compared the outcomes from all these three groups (Pakenham & Cox, 2015).

According to the Norwegian Ministry of Health and Care Services (2013), care for the ill, disabled, or elderly within the family is invisible because it is barely registered in public documents, statistics, or research on health and care services. Caring activities performed by children in Norway and several other countries have seldom been discussed in policy documents. A population-based survey of time use conducted by Statistics Norway has demonstrated that 1% of children aged 9 -15 and 2% of adolescents aged 16 - 24 provided care for ill, disabled, or elderly family members (Vaage, 2012).

Lack of Norwegian research on quality of life for children affected by parental illness

The majority of children experience their parents' illness to be stressful and report reduced well-being, while only a modest proportion of children with mentally ill or alcohol-abusing parents experienced severe consequences in the form of mental illness or neglect (Torvik & Rognmo, 2011).

The population's QoL is one of Norway's most important focuses and constitutes a separate goal in politics, community planning, and management (Nes et al., 2018). Monitoring QoL over time has been introduced as important for the promotion of public health by identifying groups at risk for poor QoL and to evaluate impact of public interventions. There has been a growing awareness of these concepts in public health policy as indicators for national statistics and research in several European countries (Helsedirektoratet, 2015; Jonsson et al., 2017; Ravens-Sieberer et al., 2006; Ravens-Sieberer et al., 2001; Ravens-Sieberer, Herdman, et al., 2014; Wallander & Koot, 2016). Norwegian health policy has underlined that public health promotion shall not only reduce the risk of illness but also promote QoL and well-being (Barstad et al., 2016; Helse- og omsorgsdepartementet, 2015; Helsedirektoratet, 2015; Nes et al., 2018). Nationally, there has been a major focus on knowledge of the population's living conditions, while knowledge of subjective well-being has been less prioritised in policy, research, and population studies (Nes et al., 2018). However, the Directorate of Health program for Public Health Work in the Communities 2017-2027 aims to promote children and youth's mental health and QoL (Helsedirektoratet, 2017). To my knowledge, at the time of our development of the multi-centre project there had been no quantitative Norwegian research on QoL in CAPI. Therefore, there has been a need to explore the impact of parental illness on various dimensions of everyday life and well-being of children in Norway. This research needs to include reports on how children experience their QoL.

2 Aims of the three papers

The overall aims of this thesis are to present my investigations of how parental physical illness, mental illness or substance abuse affects children 8–18 years old. The three papers focused on the following:

Paper I: The extent and nature of the children's caring activities
Paper II: The positive and negative outcome of the children's caring activities
Paper III: Factors associated with the children's QoL

Aims of paper I: Children with ill parents: extent and nature of caring activities

In the first paper, we examined the extent and nature of the children's caring activities when their parents received treatment as inpatients or outpatients in public hospitals. We investigated whether there were differences in caring activities across the three parental illness groups (physical illness, mental illness, and substance abuse), and whether several factors were associated with caring activities.

Aims of paper II: Outcomes for children who care for a parent with a severe illness or substance abuse

In the second paper, we examined the positive and negative outcomes for children who care for a parent who received treatment as inpatients or outpatients in public hospitals. Further, we examined whether outcomes differed between the three parental illness groups, and whether several factors were associated with the outcomes, such as the type of parental illness, parental health status, family socio-demographics, parent's access to care and social support, family functioning, the children's characteristics, the children's caring activities.

Aims of paper III: Factors associated with quality of life for children affected by parental illness or parental substance abuse

In the third paper, the aim was to explore factors associated with self-reported QoL in children affected by parental illness or parental substance abuse. As summarized above, these factors include family socio-demographics (i.e. ill parent's gender, single-parent family, level of education, level of family income), parental illness characteristics and severity (i.e. illness duration, unpredictability, health status, mental health), family functioning (i.e. family cohesion, parental capacity), parental access to care and support (i.e. home-based services, parental social support), children's characteristics (age, gender, social skills), family role redistribution (i.e. increase in responsibilities), daily hassles (i.e. nature of caregiving) and child stress responses (i.e. outcome of caregiving and feeling of control).

3 Methods

3.1 Design and recruitment of participants

I used data from a large multi-centre project which had a cross-sectional research design. We recruited ill parents from 15 services in five health trusts in three out of four health regions in Norway. At the time of writing, there was a total of 19 health trusts in Norway. The total number of inhabitants in the catchment areas of these five health trusts was 410,000 children aged 0-17, which was 34% of the population of Norway.

We recruited families in each of the five health trusts by recruiting ill parents from somatic hospitals, mental health services, and substance abuse services. The multi-centre project planned to include a total of 900 ill parents, with 60 ill parents from each of these three types of services in each health trust. This would provide a sub sample of 180 ill parents from each health trust and 300 ill parents from each of the three types of services. However, the multi-centre project received consent from a total of 534 families, which was 63% of the planned sample size.

Unfortunately, because administrative data on non-inclusion were insufficiently registered, we do not have information about how many patients were eligible or how many eligible patients asked to participate.

Inclusion criteria and procedures for recruitment of families

The papers in this thesis included a sub-sample of the total sample of the multi-centre project. The ill parent was included in the multi-centre project if all of the following criteria were met:

- The ill parent was an inpatient or outpatient in either a somatic health service, a mental health service, or a substance abuse service
- The ill parent had a severe physical illness in terms of severe neurological illness or cancer, a mental illness, or substance abuse
- The ill parent had at least one biological or adoptive child
- The ill parent provided parental care to the child at least every second weekend
- The ill parent and the child read and understood the Norwegian language
- The study received consent to participate from the ill parent, from the other parent for the child aged 8-15 and from the child 8-18
- The child aged 8- 18 filled in the questionnaires

This means that we included parents with any mental illness and parents with any substance abuse. However, we limited the group of parents with physical illness to the smaller group with severe neurological illness, mainly multiple sclerosis or cancer, according to formulations used in the law.

We recruited ill parents from one or more outpatient units and one or more inpatient units at each of the three types of services in each health trust. The Ph.D. students and members of the research teams in each health trust recruited patients and collected data on specific days or weeks at each unit. We planned to recruit ill parents who were outpatients and inpatients in a 4:1 ratio in accordance with annual national statistics on the distribution of outpatients and inpatients in such services.

Only one child from each family was included in the multi-centre project. The procedure was as follows: If the ill parent had more than one child, we mainly selected one of them by a lottery. This was done by the interviewers in advance by writing a note for each child (name or age) and blindly drawing a note. The child who was drawn received information in advance and was prepared to complete the questionnaire. If the parent did not want a lottery and preferred to determine which child was included in the survey, the interviewers respected this and noted how the selection was made as well as the reasons for the selection. The second alternative was seldom used.

The ill parents, children, and other parents were provided with written and oral information about the study, and written consent was obtained from the children and parents. Both parents gave consent on behalf of the children aged between 8 and 15, whilst children aged 16 and 17 provided their own consent.

3.2 Sample of children and parents in this thesis

The total recruitment period for the larger multi-centre project was from 1st May 2013 to 31st December 2014. The actual period varied between the services because of practical reasons. At the end of this inclusion period of 20 months, the total number of families recruited to the multi-centre project was 534, of which the present study used data from the families with children aged 8–18 years (N = 246). The ill parent was recruited first and participated for almost all the families, except that we did not receive data from 8 of the 246 ill parents, mainly because of the severity of the illness but sometimes also because they, for other reasons, did not complete the questionnaire. We did not use any data from the other parent. The parents answered questionnaires for all children between 0 and 18. More details are depicted in Table 3.2.

Table 3.2 Number of children and ill parents in the sample, specified for the different types of parental illnesses

	Physical illness	Mental illness	Substance abuse	Total
Children aged 8 to 18 years	140	76	30	**246**
Ill parent	135	75	28	**238**

3.3 Measures

The outcome measures in this thesis were children's caregiving, positive and negative outcomes of caring, and QoL. These measures were used as dependent variables in the analyses. We also measured various sociodemographic variables and characteristics of the children and their parents. We used these as independent variables to explore factors associated with children's caregiving, positive and negative outcomes, and QoL during parental illness.

3.3.1 Measures filled out by the children

The children filled out an electronic questionnaire on a tablet which the research team brought along when meeting the included family and child. The child questionnaire included a range of measures validated for use between the age 8-18 years. Most of the measures are well known and have known psychometric properties, but some measures were designed for the thesis and included papers.

The Multidimensional Assessment of Caring Activities (MACA-YC18) and The Positive and Negative Outcomes of Caring scales (PANOC-YC20) (Outcome measures)

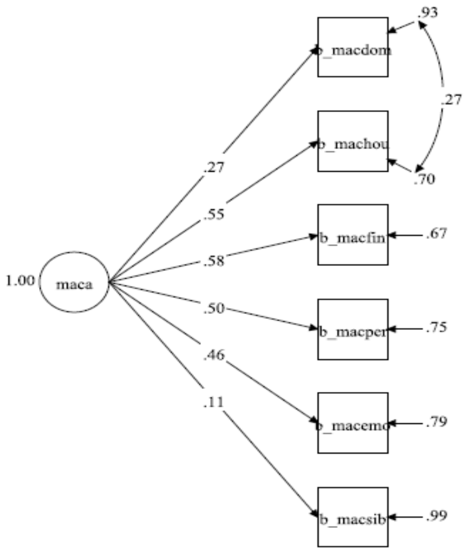
The MACA-YC18 and PANOC-YC20 (Joseph, Becker, & Becker, 2012; Joseph et al., 2009) were translated from English to Norwegian by Lona and Ulstein in 2010. By contact with Saul Becker, one of the authors of the developed instruments, he advised me to contact Lona and Ulstein which sent us an unpublished Norwegian translation of both instruments per email. The original English version of MACA-YC18 was developed from an initial item pool of 42 caring activities to reflect a range of caring activities undertaken by children. We selected three more items from the MACA-YC42 and translated it into Norwegian. The two instruments MACA-YC18, PANOC-YC20 and the three added items from MACA-YC42 were pilot tested with children of patients in clinics within all the five health trust, along with the other child measures included in the questionnaire. We adjusted the original Norwegian versions and the three items in line with feedback from the children.

The revised Norwegian versions were back-translated, compared with the original English version and approved by the authors of the original English versions of MACA-YC18, MACA-YC42 and PANOC-YC20. MACA-YC18 has six subscales, each including three items: (1) domestic tasks such as cleaning and cooking, (2) household management such as shopping, (3) financial and practical management such as helping to pay bills, (4) personal care such as helping to dress or wash, (5) emotional care such as keep company and make sure the person is alright, and (6) sibling care (Joseph et al., 2009). Each item is scored on a three-point scale (‘Never’=0, ‘Some of the time’=1, ‘A lot of the time’=2), resulting in a possible range of each subscale from 0 to 6 and the total score from 0 to 36. Higher scores indicate higher extent of caregiving. We included an additional subscale for health care with three items from the extended MACA-YC42 version (Joseph et al., 2012; Joseph et al., 2009). The health subscale is not included in the total scores or the interpretation of extent (total scores) in any of the thesis papers.

The MACA-YC18 and PANOC-YC20 are derived from item pools of MACA-42 and PANOC-75 and reduced from 42 to 18 items and 75 to 20 items, respectively, based on data from 410 young carers between 8 to 21 years in the UK who participated in interventions for young carers. The MACA-YC18 and PANOC-YC20 were validated to develop norms based on a sample of 125 young carers (Joseph et al., 2009). Joseph et al. (2009) have pointed out that they may have overestimated the normative scores of both the MACA-YC 18 and the PANOC-YC18 because the validations were based on young carers and not on children affected by parental illness or children in general. The results of their study may thereby not be comparable with the findings from the papers in this doctoral study because we included a sample of affected children, not children identified as young carers. The assessment tools developed to be completed by young people identified as young carers, was in this thesis modified to be a general measure, regardless of whether the children undertook caring activities (items 1-9, 16-18), and nine items (10-15, 19-21) specific for parental illness (e.g. item 11 ‘Help the person you care for to have a wash’ was reworded as ‘Help the one who is ill or you care for to have a wash’). In paper I, we used the interpretation of scores on the MACA-YC18, which indicates the four categories of extent: 0-9 means to a low extent; 10-13 means to a moderate extent; 14-17 means to a high extent; and 18 and above means to a very high extent (Joseph et al., 2012). However, a revised survey version of MACA-YC18 (Joseph, Kendall, et al., 2019) developed to allow it to be used with all young people regardless of their caring role were published by the authors in 2019. Cronbach’s alpha for MACA-YC18 was 0.78 for the original English version (Joseph et al., 2009) and 0.70 for the Norwegian version in our study.

Confirmatory factor analysis of MACA-YC18 – During the planning of the papers for the thesis, a confirmatory factor (CFA) analysis of MACA-YC18 was conducted. The CFA was not included in any of the papers but is presented below. The six subscales of the MACA-YC18 were entered as the indicators of the MACA latent factor in the model confirmation. The data fit the model very well: $\chi 2$ (8) = 10.43, p = .24, RMSEA = 0.04, 90% C.I. = 0.00-0.09, CFI = .98. Error variances of two of the indicators (domestic tasks and household management) were allowed to correlate. All indicators loaded significantly onto the factor, and the standardised factor loadings ranged from .11 to .58. The lower factor loading of the sibling care indicator reflects that not all children and youth in our sample had siblings. Thus, variance for this indicator was reduced because some children answered ‘not applicable’ to questions concerning the care of younger brothers and sisters (please see figure 2.) Thereby, the MACA-YC18 with the six original subscales appeared to work satisfactorily among the children with ill or substance-abusing parents. Based on the findings of the Cronbach’s alpha and the CFA, the internal validity of the MACA-YC18 measure may have been good enough to capture the extent and nature of the children’s caring activities.

Figure 2. Confirmatory factor analysis of MACA



Subscales in the CFA: _macdom = Domestic tasks, _machou = household management, _macfin = financial/practical management, _macper = personal care, _macemc = emotional care, and _macsib = sibling care.

The PANOC-YC20 is a 20-item self-reported measure consisting of subscales (10 items each) for positive and negative outcomes in terms of subjective cognitive and emotional effects (Joseph et al., 2012; Joseph et al., 2009). Each item is scored on a three-point response scale (‘Never’ = 0, ‘Some of the time’ = 1, ‘A lot of the time’ = 2). PANOC-YC20 was originally developed as an assessment tool for identified young carers, but as described above modified as a general measure, regardless of whether the children undertook caring activities based on experiences from the pilot test. Cronbach’s alphas for the positive and negative scales were 0.90 and 0.89 for the original version (Joseph et al., 2009) and 0.86 and 0.81 for the Norwegian version respectively. A CFA was not performed for the PANOC-YC20 in the present sample; however, the findings of the Cronbach’s alphas in our sample indicate that the internal validity of the measure may have been accurate enough to capture the children's experiences of the consequences of their caregiving. The PANOC-YC20 (Joseph et al., 2009) was used in Paper II and III.

MACA-YC18 and the three items of MACA-YC42 will hereby be described as the MACA. MACA was used in all three papers of this thesis to measure the extent and nature of caregiving provided by the children. The PANOC-YC20 will hereby be described as the PANOC. PANOC was used in paper II and III of this thesis to measure the positive and negative outcome of caregiving provided by the children.

Hours spent on caregiving

The question 'hours spent on caregiving' was designed for our study and used in Paper I and III: 'How many hours do you help out or take responsibility at home during an ordinary week?' The item was scored on a five-point response scale (1-4 hours = 0; 5-9 hours =1; 10-19 hours = 2; 20-49 hours = 3; 50 hours or more = 4).

KIDSCREEN (Outcome measure)

Paper III used the Norwegian KIDSCREEN-27 measure for children aged 8-18 (Andersen et al., 2016; Ravens-Sieberer et al., 2007). This measure of the children's quality of life includes available European norm data (The KIDSCREEN Group Europe, 2006) and five sub-scales: physical well-being (five items), psychosocial well-being (seven items), peer-relations and social support (four items), autonomy and parent relations (seven items), and school environment (four items). Each sub-scale is scored on a five-point scale ('Not at all' = 1 to 'Very much' = 5) (The KIDSCREEN Group Europe, 2006). Rasch-scores were computed for each dimension and calculated into T-scores (mean score = 50; standard deviation [SD] = 10) for comparison with European norm data (The KIDSCREEN Group Europe, 2006). The total KIDSCREEN raw score was generated by summing all item responses. Cronbach's alphas ranged from 0.81 to 0.84 for the original version (Ravens-Sieberer et al., 2007; Ravens-Sieberer, Herdman, et al., 2014) and 0.73 to 0.83 for the Norwegian version respectively (Andersen et al., 2016).

Confirmatory factor analysis of KIDSCREEN-27 – We conducted a CFA of the KIDSCREEN-27 for the multi-centre project which was recently published and based on the same sample as the papers in this thesis (Hagen, Hilsen, Kallander, & Ruud, 2018). The findings indicated that the KIDSCREEN-27 questionnaire fit the theoretical five-factor model of QoL reasonably well and the questionnaire therefore appeared to work satisfactorily for children affected by parental illness.

The Social Skills Rating System (SSRS)

The SSRS (Gresham & Elliott, 1990a; Ogden, 2003) is a tool for describing children's social behaviours and was included in the three papers included in this thesis. The SSRS is among the most frequently used instruments for measuring children's (aged 3–18) pro-social behaviour and problem behaviour, and a number of studies have supported its validity and reliability (Frey et al., 2011; Humphrey et al., 2011). We used the 34-item version which has four subscales for children: co-operation, assertion, self-control, and responsibility (Sørlie et al., 2008). The Norwegian version is identical to the US version except that is uses a four-point scale instead of a three-point scale ('Never' = 0, 'Sometimes' = 1, 'Often' =2, 'Almost always' = 3) (Sørlie et al., 2008). Higher scores indicate higher levels of social competence. Two different versions of SSRS were used: one for those aged 8-12 and another for those aged 13-18, which have a Cronbach's alphas of 0.92 (N = 151) and 0.90 (N = 95) in our study respectively. Cronbach's alpha was reported as 0.83 in a large American sample (Gresham, Elliott, Vance, & Cook, 2011).

Children's Locus of Control Scale

To assess the children's feeling of control, we selected 14 items from the 40-item Nowicki-Strickland Children's Locus of Control Scale (Nowicki & Strickland, 1973). The items were scored dichotomously ('Yes' = 1, 'No' = 0), and items on internal control were reversed. The total sum score ranged between 0 and 14. Higher scores indicated higher external locus of control. The questionnaire was translated from English to Norwegian with an approved back-translation procedure. Cronbach's alpha was 0.66 for the original English version (Nowicki & Strickland, 1973) and 0.37 in our study.

Children's perception of family role redistribution of responsibilities

Three questions on 'children's perception of family role redistribution of responsibilities' were designed for our study and used in paper III: 1) 'Do you undertake more responsibilities at home, due to parental illness?', 2) 'When your parent is ill, are there other adults who take on the responsibilities your ill parent usually provides?'. These were answered using a four-point scale ('Never'=0, 'Some'=1, 'Often'= 2, 'A lot'=3). Question 3) 'Do you experience too much responsibilities at home?' was answered using a three-point scale ('Never'=1, 'Sometimes'=2, 'Often or very often'=3). Higher scores on the single items indicate higher levels of family role redistribution.

3.3.2 Measures filled out by the ill parent

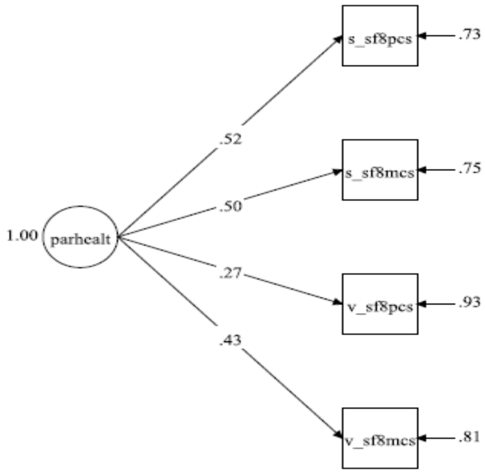
In addition to variables based on psychometric standardised measures for the parents, we also included questions on the family's demographics such as age, ethnicity, education, income, and whether the family was a single parent family. Some parental illness characteristics such as duration of illness and perceived predictability of the illness were also included. Some questions were designed for our study, such as parenting capacity, parental access to formal care in terms of home-based services and 'parent's perceptions of family role redistribution'. In all papers (I-III) I used the data reported by the ill parent in addition to the children's reports. The measures were as follows:

Health Survey SF-8

Health status was measured with Health Survey SF-8, which is a shorter form of SF-36 (Turner-Bowker, Bayliss, Ware, & Kosinski, 2003; Ware et al., 2001) and was used in all three papers in the thesis. The SF-8 includes the four-item physical component scale (PCS) which covers physical functioning, role limitations due to physical health problems, bodily pain, and general health and a four-item mental health component scale (MCS) which covers vitality, social functioning, role limitations due to emotional problems, and mental health; all these items are reported for the previous week. Each item is scored on either a five-point or six-point scale. The SF-8 has been demonstrated to be sensitive to change. The total scores of healthy adults have been reported as 53.45 and 52.72 for PCS-8 and MCS-8 respectively (Turner-Bowker et al., 2003). Higher scores indicate better health. Previously reported Cronbach's alphas were 0.88 and 0.82 for the PCS-8 and MCS-8 (Ware et al., 2001) and 0.82 and 0.80 in our study respectively.

Confirmatory factor analysis of SF-8. During the planning of the papers for the thesis, a confirmatory factor (CFA) analysis of SF-8 was conducted. The CFA was not included in any of the papers but is presented below. The four indicators were the physical and mental health of the ill parent and the other parent. These indicators were predicted by the latent variable 'parental health'. The SF-8 with its two subscales was the measure for this variable. Three cases had missing values on all *x*-variables, which made the sample size *N* = 243 for this model. The model fit the data well: χ2 (2) = 3.43, *p* = .18, RMSEA = 0.05, 90% C.I. = 0.00-0.150 and CFI = 0.96. All indicators loaded significantly onto the factor, and the standardised factor loadings ranged from .27 to .52 (please see figure 4).

Figure 4. Confirmatory factor analysis of parental health; SF-8 for both parents



Subscales: s_sf8pcs = physical component scale for the ill parent, s_sf8mcs = mental health component scale for the ill parent, v_sf8pcs = physical component scale for the other parent, v_sf8mcs = mental health component scale for the other parent.

Hopkins Symptom Check List 10 (SCL-10)

Mental health status was measured by Hopkins Symptom Check List 10 (SCL-10) (Strand et al., 2003), which is reported by the ill parent and was used in paper I and III. The SCL-10 has four questions on anxiety and six on depression that are reported for the previous week. Each item is scored on a four-point scale (from 1 = not at all to 4 = extremely), and a mean score above 1.85 indicates significant symptoms. Cronbach's alpha was 0.88 in another Norwegian study (Strand et al., 2003) and 0.91 in our study.

Family Adaptability and Cohesion Evaluation Scale (FACES III)

Family cohesion was measured with the 10-item cohesion subscale of the Family Adaptability and Cohesion Evaluation Scale (FACES III) (Ide, Dingmann, Cuevas, & Meehan, 2010; Olson, 1986; Olson, Portner, & Lavee, 1985; Vandvik & Eckblad, 1993). Family cohesion assesses degree of separation or connection of family members to the family. The scores range from extreme low cohesion to extreme high cohesion and are categorized into disengaged, separated, connected, and enmeshed family. Family members answer by estimating both the relative truth of the statements and what the family member would like in the ideal situation (e.g. family members would ask each other for help; we would know who the leader was in our family). The FACES III scale was used in all three papers in the thesis. Each item was scored on a five-point response scale ('Almost never' = 1 to 'Almost always' = 5), with higher scores indicating more cohesion. Cronbach's alpha was reported as 0.77 in a previous study (Olson, 1986) and was 0.93 in our study.

Parenting capacity

Parenting capacity during illness in the family was measured with eight questions constructed for the multi-centre project and used in all three papers of the thesis. The questions were based on a qualitative study among Norwegian families with substance abuse problems (Haugland, 2005) and two reviews of research on the impact of substance abuse, mental illness, or severe physical illness on parenting capacity (Cleaver, Unell, & Aldgate, 2011; Pedersen & Revenson, 2005). These questions address the degree to which the parents' illness has a negative influence on the parents' capacity to engage in practical work at home, ensure that the child arrives at school on time, follow-up on the child's school work, emotionally support the child, maintain structure in everyday life, follow-up on the child's leisure time activities, organizing familial social activities, and participating in social activities with the child. Each item was scored on a four-point scale ('Not at all' = 0 to 'A larger degree' = 3), with higher scores indicating lower parenting capacity. Reliability was assessed by Cronbach's alpha to be 0.91.

Interpersonal Support Evaluation List-12 (ISEL-12)

Parental social support was measured with the Interpersonal Support Evaluation List-12 (ISEL-12) (Cohen, 2008; Merz et al., 2014); the ISEL-12 was used in all three papers of the thesis. The ISEL-12 is a short form of the 40-item version (Cohen & Hoberman, 1983) which measures functional (i.e. perceived) social support. Functional social support is scored by summing the items to create an overall social support score or by three subscale scores that represent appraisal, belonging, and tangible social support. Each item was scored on a four-point response scale ('Definitely false' = 0 to 'Definitely true' = 3). The total sum score ranged from 0 to 36, with higher scores indicating more social support. Cronbach's alpha was 0.70 in a previous study (Merz et al., 2014) and was 0.86 for the ill parent in our study. In papers I and II, the significant sample differences between parents with physical illness and substance abuse were not reported on the correct 12-item version; instead, they were reported on a response scale based on the 40-item version with a total sum score between 1-48. Hence, those results were not correct. Furthermore, the Cronbach alpha of ISEL-12 was described as 0.48 in Paper I, which is incorrect; the figure was cited correctly in papers II and III. None of the other analyses in the papers (I-III) was affected.

Access to care

Access to care in terms of home-based services was measured by the item 'Do you receive home-based services to ensure your own needs?' The answer was either 'Yes' (= 1) or 'No' (= 0). The item was designed for the multi-centre project and was used in all three papers of the thesis. The item 'How many hours a week do you receive home-based services for practical help and/or emotional support?' was reported numerically, was designed for the multi-centre project, and used in paper I-III.

Parent's perception of family role redistribution of responsibilities provided by their children

Three questions on the parents' perception of family role redistribution of responsibilities provided by their children were designed for our study and used in paper I: 1) 'Has your child had to undertake caring activities at home because of your illness?' 2) 'Has your child helped you out with personal care you usually would have done yourself because of your illness?' and 3) 'Has your child taken on caring activities because health care or home-based services have not performed these activities?'. These were answered using a four-point scale ('Never = 0', 'Some = 1', 'Often = 2', 'A lot = 3').

3.4 Data collection procedures

Two trained personnel met the family at a time, usually after school and before leisure activities, and location chosen by the family, usually the family's home. The personnel were available for clarifications whilst the parent and child separately answered online questionnaires on tablets.

The children used a mean time of 45 minutes to complete the questionnaire while the parents' mean time was 60 minutes. The family received two cinema tickets as compensation for their time.

The answers were not saved on the tablets; instead, they were encrypted and transferred to an electronic database on a secure server administered by the Centre for Child and Adolescent Mental Health in Eastern and Southern Norway, which were one of the partners in the multi-centre project.

3.5 Statistical analyses

Analyses for the papers in the doctoral thesis were conducted with the Statistical Package for the Social Science (SPSS) for Windows version 23.00 (IBM, 2015)(Papers I-III). The CFA of MACA-YC18 and SF-8 for the thesis was conducted using Mplus software (Munthèn, 1998-2015). I controlled that none of the included independent variables were strongly correlated and that the dependent variables had acceptable normal distributions.

In the papers (I-III), we first used descriptive analyses to present the demographic characteristics, the extent and nature of the children's caring activities, and the positive and negative outcome of their caregiving. Then, in paper I and II differences between groups were examined using analysis of variance (ANOVA) with the Bonferroni post hoc test to examine pairwise differences in demographic characteristics, the extent and nature of the children's caring activities, and the positive and negative outcomes of those activities in relation to the three parent groups (physical illness, mental illness, substance abuse). Finally, we performed multiple linear regression analyses where all independent variables were entered simultaneously. This enabled examination of the factors associated with caring activities as measured by MACA-YC18 and of the positive and negative outcomes of the caregiving as measured by PANOC-YC20. In paper III, we conducted six multiple linear regression analyses with children's reported QoL measured by KIDSCREEN-27 (the total scores and the five dimensions) as the six dependent variables. First, we conducted a bivariate regression analysis of association with total QoL for each independent variable considered to be relevant based on previous studies or lack of previous studies. Independent variables with a bivariate association with a p value below 0.20 were included in the multilevel regression analysis, following the lax criterion recommended by Altman (1990). The independent variables measuring children's caregiving, outcome of caregiving and parents' mental health were considered important in this study and included in the multiple regression analyses regardless of significance of the bivariate association. All KIDSCREEN scores were standardised according to the KIDSCREEN manual and mean t-scores were used for each of the five KIDSCREEN-27 dimensions (47). We entered all the independent variables simultaneously into the regression analyses.

In the papers (I-III) the adjusted R square (R^2) values of the regression analyses were used to assess the fit of the statistical models. Analyses of variables were considered to be statistically significant at $p<0.05$. Data analyses were performed using SPSS 23, IBM, 2015.

3.6 Ethical aspects

The multi-centre project was approved by the Regional Committee on Medical and Health Research Ethics South-East (reg.no. 2012/1176) and by the Privacy Ombudsman at each of the five health authorities taking part in the study. The patients and families were provided with written and verbal information about the study, and written informed consent was obtained from children and parents. In accordance with The Norwegian Health Research Act, both parents gave consent for children between 8 and 15 years, while children older than 16 years provided their own consent.

4 Results

In this chapter, I summarise the results presented in the three papers included in this thesis.

4.1 Paper I: Children with ill parents: extent and nature of caring activities

Rationale: Previous studies have indicated that children may provide more caring activities if their parents are affected by severe illness or disability, especially when their parents lack access to formal and informal care.

Aims and objectives: This study examines the extent and nature of caring activities undertaken by patients' children, the differences in caring activities between different types of parental illness, and the factors associated with caring activities.

Design: An explorative cross-sectional multi-centre project.

Methods: Parents who were patients in specialised healthcare services and their children were recruited from five health trusts in Norway. The sample included 246 children aged 8–17 and their 238 parents with severe physical illness (neurological disease or cancer) (N = 135), mental illness (N = 75) or substance abuse (N = 28).

Main outcome measure: MACA-YC18.

Results: Many children with ill parents perform various caring activities. Parents confirmed that their children assumed more caring activities due to their parents' illness, especially with regard to personal care. We found no significant differences in the extent of caring activities between illness types, but there were some differences in the nature of these activities.

The factors significantly associated with the extent and nature of caring activities was better social skills and higher external locus of control among the children, as well as poorer physical parental health functioning. Parents' access to home-based services was limited.

Study limitations: A sampling bias may have occurred during recruitment of participants for the study.

Conclusion: There is a need for increased access to flexible home-based services adapted to the type of parental illness. Increased access will promote coping and prevent inappropriate or extensive caring activities among children with ill parents.

This paper incorrectly reported the Cronbach alpha and the significant difference of social support between parents with physical illness and substance abuse, because the paper used the scale for the 40-item version with a range of 1-48 instead of the 12-item version with a range of 0-36 (Cohen, 2008; Cohen & Hoberman, 1983; Merz et al., 2014). However, the usage of the different scale has not affected any of the other analyses, results, or conclusions of the paper.

4.2 Paper II: Outcomes for children who care for a parent with a severe illness or substance abuse

Rationale: The number of quantitative studies of children's caring activities during parental illness has increased in the past 10 years. However, the various outcomes for these children have been investigated less frequently.

Aims and objectives: In this study, we investigate whether children have different positive and negative outcomes when the parent has a severe physical illness, mental illness, or substance abuse problem. We also investigate whether any factors are associated with the positive and negative outcomes of the children's caregiving.

Design: A cross-sectional, explorative, and multi-centre project.

Methods: We recruited parents who were outpatients or inpatients in five public hospitals in Norway and their children. The sample included 246 children ages 8–17 and 238 of their parents who had a severe physical illness, mental illness, or substance abuse problem.

Main outcome measure: PANOC-YC20

Results: Ten percent reported negative outcomes at a clinical level of concern, and nearly half of the children reported stress. However, the outcomes were not significantly different among parental illness groups.

Positive and negative outcomes were associated with the nature of caring activities (e.g. personal care, financial and practical management, and household management), social skills, and perceived external locus of control.

Conclusions: Health professionals must provide a more comprehensive and overall assessment of the needs of parents and children. An assessment of children's caring activities and their need for adequate information should be conducted to recognise the role assumed by the child. In particular, the children's need for follow-up regarding caring activities, respite, and emotional support should be assessed so that their feelings of mastery and key skills are not neglected.

This paper incorrectly reported the significant difference of social support between parents with physical illness and substance abuse because it used the scale for the 40-item version with a range 1-48 instead of the 12-item version with a range of 0-36 (Cohen, 2008; Cohen & Hoberman, 1983; Merz et al., 2014).

4.3 Paper III: Factors associated with quality of life for children affected by parental illness or parental substance abuse

Background: There have been inconsistent findings from studies examining factors associated with quality of life (QoL) for children affected by parental illness.

Aims: The aim of this paper was to explore factors associated with self-reported QoL in children affected by parental illness or parental substance abuse.

Design: A cross-sectional multi-centre project

Methods: The sample included 246 families with children 8–18 years recruited via ill parents who received treatment at one of five health trusts for severe physical illness, mental illness or substance abuse. We performed multiple linear regression analyses to examine factors associated with the children's self-reported QoL.

Main outcome measure: KIDSCREEN-27, assessing five dimensions of QoL (physical well-being, psychological well-being, autonomy and parent relation, peers and social support, school environment).

Results: The children's self-reported QoL was positively associated with the ill parent's self-reported physical health, the children's self-reported social skills, whether other adults took over the responsibilities, provision of sibling care and provision of health care for the ill parent, and positive outcome of caregiving. The children's QoL was negatively associated with the children's self-reported responsibilities due to parental illness, provision of emotional care for the ill parent, negative outcomes of caregiving and external locus of control. The model explained 67 % of the variance in children's QoL.

Study limitations: Sampling bias may have occurred during recruitment

Conclusions: The findings suggest factors that are important for the children's QoL. Clinicians should assess whether an ill parent's physical health may influence negatively on their ability to perform daily care for their children, and clinicians can use children's self-reported QoL to identify children who are most negatively affected.

4.4 Findings across paper I, II and III

Across the three papers four factors seems to be particularly important for the children when parents are ill. The first, children’s self-report of good social skills, was associated with both that they reported more caregiving, more positive outcomes of their caregiving, and better QoL. The second, children’s self-report of more external locus of control, was associated with both that they reported more caregiving, more negative outcomes of caregiving, and reduced QoL. The third, ill parent’s report of a reduced physical health status was associated with both that the children reported more caregiving, and reduced QoL. The fourth, the children’s negative outcome of caregiving was associated with reduced QoL, while positive outcome of caregiving was associated with increased QoL.

5 Discussion

5.1 Discussion of the methodological issues

5.1.1 Design, recruitment and sample of ill parents and their children

We used a cross-sectional design, which was appropriate for investigating our descriptive and explorative research questions. We recruited ill parents from services in five out of 19 health trusts. These five health trusts are located in three out of the four health regions and serve a third of the population in Norway. This broad recruitment of parents who were either inpatients or outpatients in somatic health services (neurology and oncology), mental health services, or substance abuse services allowed for a broad sample of parents. The broad sampling sought to increase the probability that the sample would be representative across Norway and that the recruitment period would be shorter. However, we were not able to systematically monitor and ensure the recruitment process in all of the health trusts. Therefore, we do not have systematic information about how many patients were eligible and how many eligible patients were informed and asked to participate.

Our study has a large sample size (*N* = 246) compared with most other international studies of how children are affected by all three types of parental illness, especially for studies that have recruited parents from hospitals and that have collected data from both the children and their parents as informants. One study approached hospitals to recruit a sample of *N* = 100 of children aged 11-18 and their parents with physical and mental illnesses (Krattenmacher et al., 2014). Other studies approaching hospitals recruited a sample of children aged 11-17 and their parents with cancer (*N* = 168) or multiple sclerosis (*N* = 66) (Steck et al., 2007; Thastum et al., 2009). One study of *N* = 161 children aged 10–20 and their parents with physical illnesses recruited their study sample from hospitals, other health care services, and non-health care services (Sieh, Dikkers, Visser-Meily, & Meijer, 2012; Sieh et al., 2013a; Sieh, Visser-Meily, & Meijer, 2013b; Sieh, Visser-Meily, et al., 2012). Some studies recruited larger samples from other settings or institutions like schools, church groups, or universities. One of these was a large study of *N* = 336 parents with either physical illness, mental illness, or substance abuse issues and of their children aged 9–20 (Cox & Pakenham, 2014; Pakenham & Cox, 2014, 2015, 2018). Another was a large study of *N* = 410 children recruited from young carers projects (Joseph et al., 2009).

After the first half year of recruiting patients and families for our study, we estimated that we had only recruited 20% of the expected number of eligible parents. According to the protocol, the clinicians would inform eligible patients that the research team was present at the clinic and asked whether they were willing to receive further information about the study from the research team.

The research team informed and asked eligible patients to participate. However, the estimated low recruitment rate and information that was randomly received indicated that the clinicians in mental health services only informed and asked a minority of their eligible patients to meet the research team. In some of the mental health clinics, the research team became aware that the clinicians often only informed 5–10% of the patients with children about the study; in some cases, they informed no patients at all. Some clinicians in the mental health clinics and the substance abuse clinics told us that they forgot or were reluctant to inform the eligible patients about the study. Some other clinicians explained that they considered the patients to be too ill, too overwhelmed by the treatment, or to have too many other burdens at the time. Several studies have found that health care providers often avoid recruiting eligible patients to clinical research studies (Hudson, Aranda, Kristjanson, & Quinn, 2005; Sharkey, Savulescu, Aranda, & Schofield, 2010). A systematic review has indicated that clinician gatekeeping was motivated by the general assumption of vulnerability of patients coupled with an emphasis on the duty to protect patients (Kars et al., 2016). If the clinicians' justifications for protecting the more vulnerable patients are representative and common, their gatekeeping may not have been at random. Instead, the gatekeeping may have resulted in a sample that was biased towards parents having less severe illness. This may have been more applicable to parents with mental illness and substance abuse than to parents with severe somatic illness. However, we have no systematic data that can estimate or confirm any such systematic bias of the study sample as compared with the eligible patients.

The present thesis used data from a larger multi-centre project that recruited *N* = 534 ill parents with children aged 0–18 (Ruud et al., 2015). The children in the older group were informants, while the children in the younger group were not. In the present study, we only included the data from the subgroup of *N* = 246 ill parents with children in the older group (aged 8-17).

This multi-centre project recruited 72% older children (and 28 % younger) when the parents had physical illness, 39 % older children (and 61% younger) when the parents had mental illness, and 23 % older children (and 77% younger) when the parent had substance abuse issues. We do not know the reasons for these differences. It may be that parents with mental illness and substance abuse issues were more reluctant to participate if they had to include an older child (8–17 years) as an informant, while younger children (0–7 years) did not have to serve as an informant. We recruited one child from each ill parent. The ill parents provided oral or written information to their children at home after the first meeting with the research team. The research team found that some parents who were initially positive to participate withdrew their consent after we informed them that their child older than eight years should fill out the questionnaires by themselves. Recruitment of children through parents may lead to systematic differences between children who receive parental consent as participants and for those who do not (Backe-Hansen & Frønes, 2012). Although Pakenham and Cox (2014, 2015, 2018) recruited children from schools and not parents from hospitals, their sample indicated that they recruited a proportion of older children in the three groups of parental illness that was similar to the proportion in our study. Pakenham and Cox (2014, 2015, 2018) had a sample that included 79% older children with a parent with physical illness, 23% older children with a parent with mental illness, and 10% older children with a parent with substance abuse issues.

It may be that type of parental illness played a role in whether parents provided consent. There may be several reasons for this. Some parents may want to protect their children from what they perceive to be distressing for the child or for themselves as parents, especially regarding family secrets or potentially stigmatising issues (Cree, Kay, & Tisdall, 2002). Another possible explanation may be that the parents are afraid that information from the child will paint their parenting in such a 'poor light' that they refuse to allow their children to participate (Helse- og omsorgsdepartementet, 2017c). It is thus notable that The Norwegian Health Research Act was changed in 2017 to provide children aged 12–16 with the right to consent to participate in research, given certain conditions. The intention behind this amendment was to increase the likelihood that research would uncover any problematic situations for children. However, our data was unable to uncover whether there were indeed problematic situations, and if so the extent of those problems.

The study was approved by our Regional Research Ethical Committee, which demanded consent from both parents to include children younger than 16 in the study. This likely reduced the number of families included. However, it is difficult to know the precise effect this has had on our study and whether it has contributed to a more biased sample.

The parents in our sample had a higher average educational level and a lower average income level than the general population. These characteristics are in line with a previous Norwegian population study of children and young adults who had parents with cancer (Syse et al., 2012) and the Norwegian Statistics Time Survey (Statistisk Sentralbyrå, 2012b). This may be because parents with higher educational levels participate in research more often. This was the case in a Swedish population study of children's QoL (Berman et al., 2016). The lower average income level may be due to the duration of the parents' illness. In our sample, the duration was 5 years for parents with physical illness, 10 years for parents with mental illness, and 15 years for parents with substance abuse problems. Only 23% of the parents were working full time, 62% received different types of public welfare payments, and some reported no income (Ruud et al., 2015). In our study, the parents with physical illness had significantly higher levels of education and income compared to the parents with mental illness and substance abuse issues. The studies in this field have rarely reported these characteristics for their samples or subsamples (Krattenmacher et al., 2014; Pakenham & Cox, 2014, 2015, 2018).

It is probable that the recruitment process has resulted in a sample that is systematically biased to include families with children who are less affected by their parents' illness and to include more children whose parents suffer from severe physical illness than children whose parents suffer from any mental illness or substance abuse.

5.1.2 Measures and data collection

We collected data from three types of informants for each family: the ill parent, one child, and the other parent. The data provided us with the opportunity to compare differences between these groups. The children reported that they contributed more caregiving for the ill parent than what was reported by the parents. This discrepancy has been recognised in several studies of young carers. These studies have found that parents underreport children's caregiving (Aldridge, 2006; S. Becker, 2007; Pakenham & Cox, 2012a). The discrepancy between children's self-reporting and their parents' reports has been repeatedly found in the research literature. Mothers are considered to be the most valid single informant and are often the most available informant about the children's situation, health, or needs for services (Sattoe et al., 2012; Van Roy et al., 2010). However, parents have been found to be less valid informants if they are depressed. Then, they tend to report higher levels of problematic behaviour compared to a partner or teacher who is not depressed (Berg-Nielsen et al., 2003; De Los Reyes et al., 2008; Friedlander et al., 1986; Jeske et al., 2011; Najman et al., 2000; Najman et al., 2001; Ordway, 2011; Quitmann et al., 2012). Adding information sourced directly from the children may increase the validity of the study when the parent is depressed. However, it may be difficult to find the most valid way to combine multi-informant data.

In this study, we mainly used well-established questionnaires with known measurement properties. This increased the validity of our results in comparison with findings from other studies. For all measures except one, we found acceptable internal consistency as measured with Cronbach's alpha. The exception was the locus of control questionnaire, which had a low Cronbach's alpha for the 14 items selected for our study.

We had few missing answers for most of the questions in the questionnaires. A possible reason was that the online data collection system required the respondents to answer before they could proceed to the next question. This requirement did not apply when the children were answering the question about number of hours spent on caregiving. More answers were missing for this question.

5.2 Discussion of main results

The main results have been discussed separately in each paper (I-III). In this chapter, I will discuss some issues in more depth than we did in the papers.

Paper I reports that the children's caregiving at home and for the ill parent increased during parental illness or substance abuse. Across the papers (I-III) there are three factors, which seem to have particular impact on the children's outcomes of parental illness. The first, children's self-report of good social skills, was associated with both that they reported more caregiving, more positive outcomes of their caregiving, and better QoL. The second, children's self-report of more external locus of control, was associated with both that they reported more caregiving, more negative outcomes of caregiving, and reduced QoL. The third, ill parent's self-report of a reduced physical health status, was associated with both that the children reported more caregiving, and reduced QoL. The fourth, the children's negative outcome of caregiving was associated with reduced QoL.

In spite of increased amount of research, only a few studies have included both children with parental physical illness, mental illness, and substance abuse, and no reviews are published that I know of. These few studies most often used measures of caregiving and outcome (see chapter 1.6) and of QoL (see chapter 1.7) that were different from the ones we used in this thesis and included papers (I-III). To my knowledge, there are only four published reviews of children's caregiving and outcomes that cover either qualitative research, quantitative research, or both (Kavanaugh, Stamatopoulos, et al., 2015; Rose & Cohen, 2010; Schlarmann et al., 2008), and there is only one review that covers measurements (Chikhradze et al., 2017). The difference between the samples, methods, and outcome measurements used in other studies compared to those used in this thesis and included papers (I-III) made it challenging to compare the results.

5.2.1 Extent, nature and outcomes of caring activities

The first paper reported that when a parent has a physical or mental illness or substance abuse problem, the children perform more caring activities than the general population of children. More than two of ten children were making sure that the ill parent took their medicines. However, the parent's reported that access to formal external care were limited. More than two of ten parents with physical or mental illness recognised their children's increased caring activities due to parental illness, particularly with regard to personal care. Parents with substance abuse reported rarely that their children increased provision of caring activities.

The second paper in this thesis reported that the majority of the children reported positive outcomes from providing care. However, nearly half of the children reported stress, while 10% reported negative outcomes at a clinical level of concern.

The findings of extent and nature of caring activities will in the following be discussed by two studies based on samples in the general population (Nordenfors & Melander, 2017; Nordenfors, Melander, & Daneback, 2014; Vaage, 2012), and two studies that use the MACA-YC18 in a sample of CAPI (Järkestig-Berggren et al., 2018) and young carers (Joseph et al., 2009), and findings of young carers research with other types of measures than MACA.

Extent and nature compared to the general population and findings of young carers studies

A Norwegian Time use survey (Statistisk Sentralbyrå, 2012b; Vaage, 2012, 94-95), included a population based sample of children aged between 9-15 years and adolescents/young adults aged between 16-24 years. Twenty-minute interviews were conducted via telephone or home visits, and the children wrote diary entries that described their activities from the morning to the evening over two days (Statistisk Sentralbyrå, 2012a). They measured the extent and nature of children's caring activities with items similar to the items from MACA used in our study. Examples are domestic activities (e.g. cleaning and tidying the house, washing dishes, and tidying the table), household management or shopping (e.g. shopping for food), sibling care (e.g. looking after children, caring for children, or following to school or kinder garden and picking up after), and children's caregiving for an adult (e.g. caring for the ill, disabled, or elderly over 16 in the household).

A Swedish study included children from the general population (Nordenfors et al., 2014). This study recruited a sample of (N = 2,424) 15-year old school children. Their aim was to explore the prevalence of young carers in Sweden and they used the MACA-YC18 and presented the findings of caring activities and young carers in percentages. However, the MACA-YC18 was adjusted for this Swedish study, which may have impacted its comparability with our findings in paper I. They scored each MACA-item on a three-point response scale with somewhat different texts on score 1 and 2 ('Never' = 0, 'Every month/Every week'= 1, 'Several days a week/daily'= 2) compared to the original MACA ('Never' = 0, 'Some of the time' = 1, 'A lot of the time' = 2) (Nordenfors et al., 2014).

Practical tasks - domestic and household management

Regarding the MACA subscale domestic activities, we found that 68% of the children were washing dishes some or a lot of the time. The Norwegian time use survey in the general population (Vaage, 2012, p. 103) found that 11% of children aged between 9-15 years and 15% of the young people aged between 16-24 years were washing dishes. Tasks such as cleaning and tidying the house were reported by 64% of our CAPI sample (paper I, table 2), while by only 20% of those aged between 9-15 years, and by 18% of those aged between 16-24 years in the general population (Vaage, 2012, p. 103). Fifty percent of the Swedish 15-years-old school children (Nordenfors et al., 2014) reported that they were washing dishes, while 7% reported cleaning other rooms either daily or several days a week. Our findings indicate a higher provision of domestic activities than the Norwegian general population of children and adolescents as well as 15-years-old Swedish school children.

We found that (paper I, table 2) 53% of the CAPI performed household tasks such as grocery shopping some or a lot of the time. In the Norwegian time use survey (Vaage, 2012, p. 103), grocery shopping was reported by 11% of children aged between 9-15 years and by 15% of young people aged between 16-24 years in the general population. In the study of the Swedish 15-year-old school children (Nordenfors et al., 2014), 5.2% reported performing grocery shopping several days a week or daily, while 46% reported performing those tasks every month or week. Our findings indicate a higher provision of shopping for food compared to the Norwegian general population of children and adolescents.

Sibling care

We found (paper I, table 2) that 32% of the children performed sibling care (looking after and caring for siblings) on their own and 34% with adults nearby some or a lot of the time. In the Norwegian time use survey (Vaage, 2012, p. 94-95), 2% of those between 9-15 reported looking after and caring for siblings, while 1% reported playing with siblings. One percent of young people aged between 16-24 years reported looking after and caring for siblings; none of those in this group reported playing with siblings (Vaage, 2012). Ten percent of the Swedish 15-year-old school children (Nordenfors et al., 2014) reported looking after and caring for siblings on their own, while 6% reported doing so with adults nearby. Both groups did so several days a week or daily. We found (paper I, table 2) that 19% followed and picked up siblings at school some or a lot of the time, while none of the children in the SSB time survey reported doing so (Vaage, 2012, p. 103). Eleven percent of the Swedish 15-year-old school children (Nordenfors et al., 2014) reported following siblings to school several days a week or daily. This indicates a higher provision of sibling care for our CAPI sample compared to the Norwegian general population of children and adolescents and 15-years-old Swedish school children.

Emotional care, personal care and health care

We found (paper I, table 2) that 65% of the children reported that they gave emotional care – such as keeping an eye on the ill parent to make sure she or he was alright – some or a lot of the time. These results were in line with a study of children caring for an ill parent with HIV/AIDS where 63% supported their parent with emotional care (Bauman et al., 2006). Our results were also in line with a Swedish study (Nordenfors et al., 2014) with a sample of 15 years old in the general population, which found that emotional care in terms of keeping them company (54%) or keeping an eye on the parent's to make sure they were alright (53%) were provided by more than half of the children daily, several times a week or each month. While, emotional care in terms of try to make the parent to feel good (73%) were reported by the majority of the children daily, several times a week or each month. This indicates similar amount of emotional care for our CAPI sample compared with general population of children and adolescents and 15-years-old Swedish school children. The findings from the studies described above may suggest that emotional care from children to their parents may be normative behaviour in terms of learned good social skills.

We found (paper I, table 2) that 15% of the children provided personal care – such as helping the parent to dress or undress; 9% helped the parent to have a wash or shower. Two percent of the school children in the Swedish study (Nordenfors et al., 2014) provided personal care every month, while 3% did so daily. In a UK sample of young carers who participated in a support group intervention, 48% reported that they provided personal care (Joseph et al., 2009). In another study of children caring for ill parents with HIV/AIDS, 25% reported that they provided personal care (Bauman et al., 2006). This indicates a higher provision of personal care for our CAPI sample compared to the Norwegian general population of children and adolescents and 15-years-old Swedish school children.

We found (paper I, table 2) that 21% provided health care, such as taking responsibility for the ill parent’s medication, doctor’s visits, or hospital visits some of the time, while 11% did so a lot of the time. An Australian study found that health care tasks are more burdensome than domestic tasks (Pakenham & Cox, 2012a). A more recent qualitative US study of 28 caregiving youth between 12–19 years explored their administration and management of a parent’s medication (Nickels, Siskowski, Lebron, & Belkowitz, 2018). This study found that most children handling medication shared the responsibility with other family members. Still, they were involved in organisational and administrative responsibilities, had varying degrees of knowledge of the medications and lacked formal education about their responsibilities. The children experienced multiple challenges related to the task. Managing medications was associated with emotional responses and possible safety issues. Health care provided by the children (aged 5-18 years) has also been explored in a US survey of 51 parents having diabetes (Jacobson & Wood, 2004). This study found that the children were administrating medications such as testing blood glucose, interpreting results. However, nearly half of children who provided health care several days a week had no education about diabetes. Examination of children’s health care for parents because they lack access to external (formal or informal) care or other health care services has been underexplored.

Extent and nature compared to CAPI and young carers samples with the use of MACA

A Swedish study recruited a sample (N = 30) of children aged 10-18 years through support groups for CAPI experiencing parental substance abuse or mental illness (Järkestig-Berggren et al., 2018). This study used the original version of MACA-YC18 to assess the extent and nature of caring activities.

They have presented the MACA findings in mean and SD, and these findings are overall in line with our results reported in Table 4 in Paper I. However, we have not tested this comparison statistically and another limitation of this comparison is that the Swedish study had a higher representation of CAPI placed in out-of-home care.

Joseph, Becker, and colleagues (2009) published a UK study based on a sample (N = 410) of young carers receiving a support intervention for their caring activities (see chapters 2.2.8 and 3.3.1). The study's aim was to develop and validate the MACA-YC18 and the PANOC-YC20.

The Swedish study by Järkestig-Berggren and colleagues (2018) found a lesser extent of caregiving provided by the children participating in the Swedish support groups than Joseph et al (2009) found that their sample of young carers provided. This discrepancy may be due to different samples. Joseph et al. (2008) have pointed out that their study had high extent of caregiving (total score and subscales) because the sample included children and adolescents who participated in interventions for identified young carers.

Extent of caregiving – measured as number of activities, how often the children provide care or time spent?

There are different ways to report the extent of children's caregiving. It may be reported by the number of different caring activities, by how often the children provide care or by the time spent on caregiving (Dearden & Becker, 2004; Joseph et al., 2009). We measured extent of caring activities in all these ways, the first two ways with the use of MACA and the last by children's self-reports of hours spent on caregiving (see chapter 3.3.1 for more details). Table 3 in Paper I give these results. However, I have improved that table (see Table 1 here) and will discuss these results in more detail. Table 1 shows that 10.2% (5.7% + 4.5%) of the children in our study of CAPI had high (score 14-17) or very high (score 18-36) total scores, compared to 17% who had a total score of 16 or more in the Swedish study of children in support groups (Järkestig-Berggren et al., 2018). Seven percent of the Swedish school children reported a very high extent of care (Nordenfors et al., 2014), while we found that 4.5% reported that level. The lower extent of caregiving reported by our sample compared to the two Swedish studies might be due to differences in samples, recruitment, methods, or cultural differences. However, it is still a considerable figure that 10.2% of the children in our study reported that they provide a high or very high extent of caring activities. This is also in line with the children's reporting on how much time they spent on caregiving.

Table1 Descriptive statistics of children's self-report of their caring activities

			Children of parents with:					
	All children		physical illness		mental illness		substance abuse	
MACA extent total score[1]	%	N	%	N	%	N	%	N
Low[2] (score 0-9)	65.4	161	59.3	83	69.7	53	83.3	25
Moderate (score 10-13)	24.4	60	29.3	41	22.4	17	6.7	2
High (score 14-17)	5.7	14	4.3	6	7.9	6	6.7	2
Very high (score 18-36)	4.5	11	7.1	10		0	3.3	1
Total	100.0	246	100.0	140	100.0	76	100.0	30
Hours spent on caregiving each week[3]	%	N	%	N	%	N	%	N
1-4 hours	59.5	50	63.5	33	60.0	12	41.7	5
5-9 hours	28.6	24	32.7	17	15.0	3	33.3	4
10-19 hours	9.5	8	3.8	2	20.0	4	16.7	2
20-49 hours	1.2	1		0	5.0	1		0
More than 50 hours	1.2	1		0		0	8.3	1
Total	100.0	84	100.0	52	100.0	20	100.0	12

[1] MACA extent total score is the total score of MACA-YC18 which is a children's self-reported amount of caring activities.

[2] The categories low, moderate, high and very high are from Joseph et al (2009). The scores in the parentheses are the range of scores for the quartiles of MACA-YC18 total score in their young carers sample from the United Kingdom.

[3] Hours spent each week is assessed by a question with the specified response categories. The question was designed for the present study and answered by the children.

Our results regarding how much time the children spent on caregiving are in line with the findings from the Statistics Norway's Time Survey (Vaage, 2012, p. 103). In our sample 59.5% of the children reported that they performed approximately 1-4 hours on caring activities each week and 28,6% reported 5-9 hours each week. The average for children in general in the time survey was 1.11 hours each day for those between 9-15 years who performed any household tasks (Vaage, 2012, p. 94). The average for the study on young carers in the UK was 12.25 hours a week (Joseph et al., 2009). We found that 9.5% spent 10-19 hours per week (Table 1). The Statistics Norway's Study of Living Conditions and Health 2015 indicated an increased governmental awareness that unpaid caregiving might affect the caregivers' health, whether this is provided by adults or young adults and whether this includes practical help to ill, disabled, or elderly parents inside or outside of their household (Helsedirektoratet, 2018; Isungset & Lunde, 2017). The Statistics Norway's Time Survey 2000 and 2010 (Vaage, 2012) has reported on the extent to which children between 9-15 years of age provided care for ill, disabled, and elderly family members. While the Survey of Living Conditions and Health 2015 (Isungset & Lunde, 2017) also included the nature of caring activities and the amount of hours spent it restricts the inclusion of adolescents to those from the age of 16 and over. Hence, it is not possible to compare results even if the survey measures activities are similar to the present study.

Parents' recognition of family role redistribution and the children's caring activities

In our study (paper I), the ill parents confirmed the reported caring activities reported by their children, especially regarding provision of personal care. Parents with physical (28%) and mental illness (21%) reported in a higher degree than the parents with substance abuse (3%) that the children performed more caring activities due to their illness. The children who experienced parental substance abuse reported the same extent of caring activities as the two other groups. This lack of recognition by parents with substance abuse may be understood in relation to their reported high parental capacity to take care of their children's needs, or lack of insight in impact of their abuse. These findings are in line with previous findings that family role redistribution is common and probably an important coping mechanism for families affected by parental illness (Bogosian et al., 2014; Morley et al., 2010; Pakenham & Cox, 2012a, 2012b; P. Patterson et al., 2013; Pedersen & Revenson, 2005; Razaz et al., 2014; Rolland, 1999; Sieh, Visser-Meily, et al., 2012). However, a recent UK governmental study has demonstrated that the majority of parents to young carers were keen to reduce the impact of the children's caregiving, particularly regarding social activities, relationships, and under-engagement in education (Cheesbrough et al., 2017).

Examination of positive and negative outcomes of the caregiving compared to other studies

Outcome of caregiving will be discussed in relation to four studies which have assessed the positive and negative consequences by PANOC-YC20. The two first studies are the mentioned Swedish study by Järkestig-Berggren (2018) and the UK study by Joseph and colleagues (2009). The third is a retrospective study from the US with a sample of 120 undergraduate students aged between 18-25 years who, before they were 18 years old, had lived with a depressed parent for a minimum of 2 years (Mechling, 2015). The fourth is also a retrospective study from the US with a sample of 30 former young carers between 19 and 56 years old (Shifren et al., 2014).

The comparability of these four studies to our study (paper II) has limitations, particularly due to the lack of statistical variance analysis that compares means (such as ANOVA), but also because of the different age groups, samples, and methods. With these limitations in mind, our findings of more positive outcomes compared to the negative outcomes of caregiving activities (paper II, table 4) are in line with all these four studies. It is worth mentioning that in spite of the differences in the samples, providing care was overall experienced to be more positive than negative, both prospectively and retrospectively. However, 10% of the children in our study (Paper II, Table 3) reported negative outcomes at a level of clinical concern, such as reporting that life did not seem to be worth living or that they felt so sad that they could not handle it. This group of children provided more adverse types of care associated with more of an adult responsibility and this may have severely impacted their well-being. Hence, our study supports previous findings of the necessity of identifying children who need effective interventions such as adequate information, respite and emotional support (Aldridge, 2017; Bjorgvinsdottir & Halldorsdottir, 2014; De Roos, De Boer, & Bot, 2017; Hamilton & Cass, 2017; Kavanaugh, Stamatopoulos, et al., 2015; Leu & Becker, 2016; Moore, McArthur, & Morrow, 2009; Nicholson & Friesen, 2014; Rose & Cohen, 2010; Stamatopoulos, 2018).

5.2.2 Extent, nature and outcome of caregiving across parental illness groups

We found that neither the extent nor outcomes of children's caring activities differed between the parental illness groups, while the nature of those activities did. These findings will be discussed in relation to studies of Pakenham and colleagues (2010a, 2010b; 2014, 2015). Our sample size was similar to the sample size of Pakenham and colleagues and they also had a skewed sample like we had (see chapter 5.1.1).

We found that the children who had a parent with physical illness reported significantly more domestic and emotional caretaking than the children who had a parent with substance abuse. However, in a regression analysis (see paper I, table 5) the difference was not significant ($p = 0.055$) for the emotional caretaking. However, there was a trend towards more emotional care for parents with physical illness. The difference between children's provision of more emotional care for parents with physical illness than for parents with mental illness was significant ($p = 0.030$) in this regression model. There was also a trend towards less emotional care provided by the children for parents reporting poorer mental health status ($p = 0.057$). We did not find differences in the total extent of caring activities between the illness types. This is in line with the studies of Pakenham and colleagues (2010a; 2014, 2015). One study has indicated more negative outcomes of the children's caregiving when parents have mental illness compared with physical illness (Ireland & Pakenham, 2010b). However, the findings from a recent study are in line with our findings (Pakenham & Cox, 2015).

5.2.3 Factors associated with extent, nature and outcome of caregiving, and QoL

Factors related to the conditions of the family

We found that low family income was associated with increase in children's health care for their parents. Other studies of young carers have found that low family income is associated with increased caregiving (S. Becker, 2007; Kavanaugh, 2014; Nagl-Cupal et al., 2014). We found that both family income and mental health of the parent (measured with the SCL-10) was negatively associated with the children's QoL only in the bivariate analysis and not in the multiple linear regression analysis (Paper III). The ill parents reported family income levels somewhat below the general population and there were some differences in income across the parental illness groups, as previously described for this sample (paper I and II).

We found that parents' self-reported physical health status was negatively associated with total extent of children's caregiving and with household management. This is in line with the previously mentioned study of children caring for ill parents with HIV/AIDS which found a positive association between severity of the parental physical disability and increased children's caregiving (Bauman et al., 2006). Overall, the multilevel regression analysis indicated that among the parental factors, only physical health of the ill parents was positively associated with the children's QoL.

Child-centred well-being factors

Child characteristics

We found that the *children's age and gender* were associated with the nature of the caregiving: being a girl and of a higher age was positively associated with a higher extent of domestic activities (e.g. cleaning and cooking). These findings are in line with those from the general population of Norwegian children (Statistisk Sentralbyrå, 2012a; Vaage, 2012, p. 94-95). The age of the child was negatively associated with personal care (e.g. helping to dress or wash). The association between younger age and personal care is in line with the findings of Pakenham and Cox (2015). It might be easier for ill parents to ask younger children to help out with more 'intimate' caretaking compared to asking adolescents. As previously described for this sample, being a girl and of higher age was negatively associated with children's QoL (Hagen et al., 2018). In line with a previous study (Pakenham et al., 2006), the number of siblings was positively associated with increased sibling care (e.g. taking siblings to school, looking after siblings alone or with an adult nearby).

We found that the children's self-reported *social skills* (i.e. co-operation, assertion, self-control and responsibility/empathy) were positively associated with the extent of caregiving (total scores of MACA-YC18) and nature in terms of domestic activities, household management, and emotional care (e.g. keeping ill parents company and watching them to ensure that they were alright). Previous prospective studies of parentification have demonstrated that children's social skills and empathy have been positively associated with emotional caregiving, although they were not positively associated with instrumental caregiving (Champion et al., 2009; Stein et al., 2007; Tompkins, 2006; van der Mijl & Vingerhoets, 2017). In these studies, it was unclear whether the children's social skills and empathy were due to the provision of emotional caregiving or whether the emotional caregiving was the result of social skills and empathy. Our findings suggest that the improved social skills (e.g. empathy) made the children able to take on emotional caregiving. The association between children's adjustment such as prosocial behaviour and the increased extent of caring activities are well known from the research on parental illness and young carers (Ireland & Pakenham, 2010a, 2010b; Järkestig-Berggren et al., 2018; Pakenham & Cox, 2012a, 2018).

We also found that better social skills were associated with more positive outcomes and less negative outcomes from caregiving (paper II, table 5). These findings are in line with three papers which indicated a positive association between the outcome of caregiving for ill parents and improved social skills such as prosocial behaviour (Ireland & Pakenham, 2010b; Pakenham & Cox, 2012a, 2018).

Providing caring activities has previously been demonstrated to lead to children developing new skills, knowledge, and perceived maturity in terms of a sense of independence and personal growth (F. Becker & Becker, 2008; Cox & Pakenham, 2014; Pakenham & Cox, 2012a, 2014; Razaz et al., 2014). One study has indicated that the ability to take on the perspective of others fostered children's empathy and reduced antisocial behaviour (Eisenberg, Zhou, & Koller, 2001). Children who have experienced concern for others are more likely to feel responsibility for the well-being of others and behave in ways that benefit others (Spinrad & Eisenberg, 2017). A study by Weinstein and Ryan (2010) has indicated that when individuals help others in need, they experienced greater autonomy, relatedness, and competence. Satisfying needs enhanced the helper's sense of well-being and benefited the recipients of help. These recipients experienced greater benefits from autonomous helpers potentially due to enhanced feelings of closeness and the receipt of better quality help (Weinstein & Ryan, 2010). The motivation for helping is that prosocial behaviour increase the well-being of the helper (Holte et al., 2014).

We found that social skills were positively associated with the children's overall QoL (total score) and the three QoL dimensions physical well-being, social support and peers, and school environment. These findings are in line with an earlier KIDSCREEN study of QoL by Detmar and colleagues (2006). Studies of children's subjective well-being have indicated that social responsibility, moral agency, and the feeling of being a good person are important positive factors for children's well-being. These are manifested at home and in personal life by helping out friends and looking out for parents (Fattore et al., 2016; Spinrad & Eisenberg, 2017). Children's moral emotions and behaviour are thought to play an important role in children's well-being (Spinrad & Eisenberg, 2017). Some examples of interactions that may shape children's positive sense of self and feelings of well-being are helping out by doing one's share, supporting and caring for family members, and trying to meet the expectations and guidance of parents (Fattore et al., 2009). Furthermore, children's emotional life and relationships, as well as a balance between positive and negative experiences, have been related to a positive sense of self and well-being (Fattore et al., 2009).

Family role redistribution

We found that *family redistribution,* in terms of children's reports of more responsibilities due to parental illness, was negatively associated with their general QoL and the psychological well-being dimension of QoL. Experiencing other adults taking the ill parent's responsibilities was positively associated with their general QoL, and two of the QoL dimensions, psychological well-being, social support and peers. However, only 29% of CAPI reported that the other parent managed to take over a lot the responsibilities of the ill parent (paper III). There was a clear discrepancy between what the children experienced and what the other parent/partner of the ill parent reported. In previously presented findings from the multi-centre project we found that more than 60% of the other parent/partner reported that they were able to take over a lot of the responsibilities of the ill parent (E.K. Kallander & Vallesverd, 2015). On the other hand, the other parent/partner reported that the hardest part of being an adult carer was the challenge to combine care for both the ill parent and the children while being in full time work with no rights to sick leave (Ruud et al., 2015).

Daily hassles

We found no association between the extent and nature of caring activities in bivariate analyses with the total scores of QoL. This finding is in line with a recent Swiss prevalence study of young carers (Leu et al., 2019).

We found that *personal care* was positively associated with negative outcomes of caregiving (paper II). A qualitative study from Iceland has found that children who provided intimate physical and emotional care for their parents felt doing so was demanding, embarrassing, and difficult (Bjorgvinsdottir & Halldorsdottir, 2014). The children felt unsupported and left alone with inescapable responsibilities. However, personal care was positively associated with the psychological well-being dimension of QoL (paper III), which is in line with some studies which found better relationship between the child and the ill parent (East, 2010; Pakenham & Cox, 2012a, 2012b).

We found no association between *emotional care* and positive or negative outcomes of caregiving, which is in contrast to Joseph and colleagues (2009) who found association with negative outcome. However, we found negative association between emotional care and overall QoL (total score), but no associations with the five QoL dimensions. According to Eisenberg, Spinrad, and Cumberland's (1998) socialisation of empathic model, parents' emotion-related socialising behaviour is effective in facilitating emotion learning when they promote children's emotional involvement. Another study of children's empathic responses to their mother's distress, indicated that personal distress may motivate attempts to understand their mother's emotions as a self-soothing strategy, and support that there are individual differences in children's empathic response (Tully, Donohue, & Garcia, 2015). This is in line with another study, which indicated that children's contribution in families and at home, both emotional and instrumental, was beneficial for the children (Armstrong-Carter, Ivory, Lin, Muscatell, & Telzer, 2019). Children are socialised into providing emotional care by their parents as a part of learning emotions (Eisenberg et al., 1998) and that the emotional care may increase during parental distress, e.g. parental illness (Tully et al., 2015). While emotional care may be normative behaviour like instrumental contribution, it does not mean it is easy to provide, whether the provider is a child or an adult.

We found no association between *health care* (e.g. make sure parents take their medicine, talking to doctors or hospitals about ill parents) and negative outcomes of caregiving (paper II), which is in line with two studies from the US, where multiple challenges were related to the children's provision of health care, particularly regarding administrating medication (Jacobson & Wood, 2004; Nickels et al., 2018). However, we found positive association between health care and overall QoL (total score) and the psychological well-being dimension of QoL (paper III).

Child stress response

We found that children's self-reported *external locus of control* was positively associated with extent and nature of caregiving in terms of household management (e.g. shopping or carrying heavy things), personal care, and health care. Locus of control is related to children's behaviour, their perception of whether they have control in their lives, and how they can control events that may affect them (Manger & Eikeland, 2000; Rotter, 1966). Parental illness or substance abuse may place children in a context that they cannot control. This might further impact the external locus of control, which is understood to be their perceptions of event outcomes that they cannot control (Culpin, Stapinski, Miles, Araya, & Joinson, 2015; Galvin et al., 2018; Haine, Ayers, Sandler, Wolchik, & Weyer, 2003; Roazzi, Attili, Di Pentima, & Toni, 2016). In line with previous studies (Burnett et al., 2006; Mauseth & Hjalmhult, 2016), our findings may indicate that the children's efforts to assume caring activities were attempts to cope with or control a situation that was out of their control. External locus of control was also positively associated with negative outcomes of caregiving, which is in line with the findings of a study by Williams and Francis (2010). Taking on caregiving may convince the caregiver that it is possible to control an uncontrolled situation (Burnett et al., 2006; Mauseth & Hjalmhult, 2016). Recent research has demonstrated that children's subjective well-being and control over everyday life were important for feelings of mastery and self-efficacy (Fattore et al., 2009).

External LoC was negatively associated with overall QoL (total score) and a trend towards the psychological well-being dimension of QoL. This finding is supported by a Norwegian qualitative study of adolescents whose parents have multiple sclerosis which found that the uncontrollable life situation due to living with an unpredictable parental illness affected them negatively (Mauseth &

Hjalmhult, 2016). Our findings are consistent with previous studies indicating positive association between social skills and QoL (Detmar et al., 2006) and negative association with negative outcome of caregiving (Fraser & Pakenham, 2009; Pakenham et al., 2006; Pakenham et al., 2007; Pakenham & Cox, 2012a).

We found that *positive outcome of caregiving* was positively associated with QoL in general, psychological well-being, autonomy and parent relation. *Negative outcome of caregiving* was negatively associated with child QoL in general and all of the five QoL dimensions. An Irish Time survey (Lloyd, 2012) and the Swiss study (Leu et al., 2019), which both used the shorter KIDSCREEN-10, indicated slightly lower QoL among young carers compared with children who had no caring responsibilities.

Children's caring skills related to illness

The development of basic caring skills among informal caregivers has been highlighted as being important for adult carers but has not been highlighted for young carers (Sprung & Laing, 2017). Young carers who provide care on a day-to-day basis are often unrecognised and unsupported. According to Sprung and Laing (2017), meeting carers' needs is a requirement of the specialist standards for education and practice and therefore is a high priority for all specialist community practitioners who work as general practice nurses. It has also been argued that young carers need the ability to develop skills, mastery, and social support regarding the care they provide (Kavanaugh, Howard, & Banker-Horner, 2018). Our findings indicate positive association between self-report of good social skills and more caregiving, more positive outcomes of their caregiving, and better QoL. Moreover, positive association between children's self-report of more external locus of control and more caregiving, more negative outcomes of caregiving, and reduced QoL. These findings may suggest the children need to develop basic caring skills related to the illness, in line with previous findings related to the children's burdens of responsibilities such as health care for the ill parent (Jacobson & Wood, 2004; Nickels et al., 2018).

To summarize, these findings suggest that during parental illness children's social skills enable them to provide caregiving and to cope. However, the findings also indicate that having inadequate skills to perform the caring activities and a feeling of lack of control may negatively impact their outcome of caregiving and QoL. Moreover, that the most important factor related to the conditions of the family for children's well-being is reduced parental physical health status, i.e. physical functioning, in terms of role limitations due to physical health problems, bodily pain, and general health. The findings also suggest that negative outcome of caregiving was the most important child-centred well-being factor for their QoL along with poor social skills and external locus of control.

5.2.4 Comprehensive understanding of the results

We found that the children affected by parental illness or parental substance abuse perform more caregiving at home and for their parent than other children do. More than half of the children experienced more responsibilities at home due to parental illness and two thirds for parents with physical illness. One third experienced too much responsibility due to parental illness. Poorer QoL was associated with older age of the children, being a girl, that the child reported more responsibility due to parental illness, and more negative outcomes of their caregiving. Better QoL was associated with the child experiencing that other adults took over the responsibilities that the ill parent usually had, the child reported provision of health care to the ill parent and more positive outcomes of caregiving.

Different ways to estimate prevalence of young carers

The Norwegian Ministry of Health and Care Services (2017b; 2011) has previously stated that informal carers provide approximately 50% of all home care in Norway today, but are almost invisible. This applies even more for the children's caring activities due to parental illness. The Ministry of Health and Care Services (2013) has also pointed out that the Norwegian society will face major challenges regarding formal care needs in the decades to come. These challenges cannot be addressed by municipal health and care services alone. Therefore, the Ministry of Health and Care Services (2013, 2017b) has described the need to provide necessary carer support in the form of respite, information, knowledge, and guidance to adult carers who provide extensive care. The ministry has also stated that most people want to help their parents or family members who are in need of care or assistance due to illness or disability (Helse- og omsorgsdepartementet, 2013, 2017a). However, the children are not acknowledged by policy as caregivers who must provide extensive or appropriate types of care due to unmet needs in the family and lack of informal and formal external care. Based on the overall findings in this thesis and included papers (I-III) the ministry's three statements for adult carers may also apply to children:

1) Children provide caring activities similar to adult carers and may also provide extensive care
2) Most children want to help their parents when they need care due to illness or impairment
3) There is a need to provide necessary carer support in the form of respite, information, knowledge, and guidance to young carers who experience negative outcomes which affect their QoL

Prevalence of Norwegian young carers

National statistics do not clarify the numbers of the Norwegian young carers under the age of 16 years. However, research has demonstrated several challenges to estimating and comparing the prevalence of young carers (Aldridge, 2017; Kelly et al., 2017). The two main challenges are that the definitions of young carers have changed through the years of research and that the differences in samples and instruments make comparisons difficult.

A definition of young carers based on *the nature of caring activities* and on activities that children do not usually perform for healthy parents, such as *personal care* or *health care*, indicates a prevalence of 15-21% (Bjorgvinsdottir & Halldorsdottir, 2014; Nickels et al., 2018)(paper I, table 2). A definition based on *care for a sibling without presence of parents*, an activity which is more commonly performed by children generally, indicates a prevalence of 39% (Falch-Eriksen, 2017; Haxhe, 2016; Stamatopoulos, 2015). A definition based on *emotional care* which was defined as destructive within the 'older' parentification literature may indicate a prevalence of 64% (Boszormenyi-Nagy & Krasner, 1986; Boszormenyi-Nagy & Spark, 1973; Bowlby, 1977; Haxhe, 2016; Minuchin, 1967). Overall, a prevalence rate based on the nature of caring activity indicates a prevalence of 15-64% of young carers in a sample of CAPI (paper I, table 2).

The *extent of very high amount of care* may indicate a prevalence of 4.5% in our sample (paper I table 3 or see chapter 5.2.1 table 1). A prevalence estimate based on *hours spent on caring activities* indicates that 11.9% reported more than the 10 hours average per week reported by children in general. Overall, based on the extent and time spent on caregiving, the findings indicate a prevalence of 5-12% of young carers in a sample of CAPI (paper I, table 3, or chapter 5.2.1 table 1).

To summarise, the different ways to estimate prevalence of young carers among CAPI in our study, indicates a considerable variety of prevalence figures (paper I).

Prevalence of Norwegian young carers who provide extensive care

The Norwegian Directorate of Health (2018, p. 7) and Ministry of Health and Care Services (2017b, p. 19) has defined extensive care for adult carers but not for children. This choice may be due to cultural norms that children should not provide extensive care, which has also been acknowledged by the Ministry of Child and Equality (NOU 2009: 8; NOU 2012: 5) and the Norwegian Directorate for Children, Youth and Family Affairs (2011). Although the government wishes to protect children from providing extensive care, it is still important to publish knowledge of the prevalence of that provision even with the methodological limitations in mind. Access to legal rights for adult carer support has been defined by the Norwegian Directorate of Health (2018, p. 7) as assessing whether the adult carer or young adult carer over the age of 18 provides 'extensive care'. Claiming necessary carer support due to extensive care should be based on the amount of care (hours per month), physical and mental stresses, if the unpaid care is regular or periodic, expected duration of care, if the carer is caring for parents with children under 18 and has income loss (Helse- og omsorgsdepartementet, 2017b; Helsedirektoratet, 2018, p.7). Furthermore, the municipality should conduct an individual assessment of the carer's situation, such as the carer's ability to maintain the care situation over time. Social conditions should also be emphasised, such as the carers' ability to maintain their work. To my knowledge, there is no available prevalence rate for adult carers with extensive care.

I will use the Norwegian Directorate of Health's (2018, p. 7) and Ministry of Health and Care Services (2017b, p. 19) definition of extensive care for adults to indicate the prevalence of young carers who conduct extensive care within the sample of CAPI based on the findings from the papers (I-III). In this thesis the term 'extensive care' is measured by the nature, extent, and hours spent per week on caregiving (paper I); the subjective, cognitive, and emotional outcomes of caregiving for ill parents (well-being) (paper II); and how these factors are associated with quality of life (paper III).

Based on the findings in Paper I, I indicated prevalence between 4.5-64% for young carers in the sample of CAPI, which is not a very precise figure. However, nearly 12% of the CAPI sample reported more than the 10 hours' average per week (paper I). According Statistics Norway children in general provide work and care at home more the nine hours a week (Vaage, 2012). Nearly half of the children reported feeling stressed, while 10% of the CAPI reported levels of negative outcome at a level of clinical concern (paper II). Hence, more hours spent and negative outcomes are associated with reports of lower levels of QoL (paper III). I use these figures to indicate the prevalence of extensive care provided by CAPI. Overall, the results of papers (I-III) indicate that the CAPI sample's prevalence rate of young carers who conduct extensive care is between 10-12%. However, as discussed in chapter 5.1, the papers included in the thesis have limitations due to a sample systematically biased towards children who are less affected by parental illness, which may have created more positive findings than for a general sample of CAPI.

Identifying different aspects of the children's caregiving such as how caregiving impacts their well-being (paper II); QoL (paper III); and the nature, extent, and hours spent on caregiving (paper I) contribute to a better understanding of extensive care and the impact of caregiving. With the limitations in the sample and methods in mind, the findings indicate that 10-12% of children affected by parental illness provide extensive care as young carers.

Young carers who provide extensive care at home and in their family - a result of poor parenting competence or structural shifts in welfare such as formal health and care services?

Due to our western cultural norms for children as recipients of care, we may be 'blaming the victims' due to their and their parents' unmet needs as ill (Aldridge & Becker, 2003). Norwegian children's involvement in care and domestic work is currently not framed within a broader context, e.g. human ecology by Bronfenbrenner (1977; 1998), nor received attention in national research compared to research of child labour in other parts of the world (Joseph, Sempik, Leu, & Becker, 2019; Nilsen &

Wærdahl, 2015). Thereby, according to Saul Becker (2007; 2019), each country need national research of international well-researched social problems to make changes in national policy.

Children's caregiving due to lack of access to informal and formal external care

The parents' lack of access to formal external care may be due to deinstitutionalisation and shorter hospital stays, a shift from inpatient to outpatient care in public hospitals and from public hospitals to primary health care. These changes have increased the number of parents who live at home with more severe illness while they are in active treatment, and their need for more informal and formal external care in their own homes. This leaves the children with no choice but to live in close proximity to parents with severe illness for longer periods of time and forces them into unavoidable caring activities (East, 2010; Gladstone et al., 2006; Mordoch & Hall, 2002). Other structural factors include women entering the work force and the decentralisation of families; grandparents no longer live near other family members (Stamatopoulos, 2018). High employment of Norwegian and Nordic women (OECD, 2018) in parallel with the downsizing and removal of home-based help at home due to illness (Borgan, 2012) may also have had considerable impact on the children's extent or nature of caregiving. These structural factors may also have had consequences for children's well-being in times of illness in the family. However, the children reported better QoL when other adults provided the responsibilities of the ill parents, while parents' access to external care was limited to 6%.

Changes in findings within 'older' research compared to 'new' research of parentification

Within the 'new' parentification studies, parentification have been found to be positively associated with social skills (Champion et al., 2009; Stein et al., 2007; Tompkins, 2006; van der Mijl & Vingerhoets, 2017), and that internal locus of control adjusted outcome of parentification positively (Burnett et al., 2006; Williams & Francis, 2010). Moreover, that the children's level of empathy is positively associated with the level of emotional care provided for adults (Champion et al., 2009; van der Mijl & Vingerhoets, 2017). However, 'older' parentification theories imply that emotional care is the core of the process of destructive parentification, which impacts the process of the child's development (attachment, security, trust and self-esteem), compared to instrumental care without emotional burdens, which does not lead to parentification (Haxhe, 2016). One concept within the parentification literature is parent-child role confusion, defined as disorganised attachment, and linked to theories of attachment and family therapy (Byng-Hall, 2002; Meier & Bureau, 2018; West & Keller, 1991). Some reviews of the parentification research literature have challenged this theoretical framework of children's caregiving (Barnett & Parker, 1998; Earley & Cushway, 2002; Haugland, 2006; Haxhe, 2016; Macfie, Brumariu, & Lyons-Ruth, 2015). Central parentification theorists, Boszormenyi-Nagy and colleagues (1986) and Jurkovic and colleagues (2004), have stated that children's caregiving is a normative component in child-and-parent relationships and should therefore not be defined as a relation disorder or attachment disorder (Godsall et al., 2004). There are a few young carers studies which have demonstrated an association between good parent-child attachment and increase in the children's caregiving (Bauman et al., 2006; Ireland & Pakenham, 2010b; Pakenham & Cox, 2013). However, Ireland and Pakenham (2010b) have demonstrated that parents with physical illness had significantly better attachment to their children compared to parents with mental illness. There is a need to develop a new understanding of emotional care for parents as learned normative behaviour, in line with the previous research findings of important factors for well-being (Eisenberg et al., 2001; Fattore et al., 2009; Spinrad & Eisenberg, 2017).

Emotional care as pro-social behaviour provided by both CAPI, young carers and children in general

We found that emotional care is commonly provided by CAPI, and particularly for parents with physical illness (paper I). This finding is in line with other study findings with samples of CAPI (Bauman et al., 2006; Järkestig-Berggren et al., 2018) in research with samples of young carers (S. Becker & Sempik, 2018; Joseph et al., 2009; Pakenham & Cox, 2012a), and as well in research with samples of general population (Armstrong-Carter et al., 2019; Fattore et al., 2009; Nordenfors et al., 2014; Spinrad & Eisenberg, 2017; Tsai, Gonzales, & Fuligni, 2016). Moreover, emotional care in our study was positively associated with social skills (paper I), which is in line with several other studies (Champion et al., 2009; Stein et al., 2007; Tompkins, 2006; van der Mijl & Vingerhoets, 2017). More children with physically ill parents provided emotional care than those with mentally ill parents (paper I); this has been supported by Ireland and Pakenham (2010a). However, there was no association between emotional care for parents and the negative or positive outcomes of caregiving (paper II). Joseph et al. (2009) have demonstrated that positive and negative outcomes were associated with emotional care for girls and not for boys. There is a question of the inherent meaning of the performance of emotional care to the child: this may impact children differently, depending on whether the parent has a short term illness or a chronic and life-threatening illness. In the latter case, the child may need emotional support themselves.

Spinrad and Eisenberg (2017) have argued that whether children provide appropriate responses to others in need or distress (e.g. concern, helpful behaviours) have important implications for positive social functioning, such as social competence, socially appropriate behaviours, and unproblematic behaviours. The ability to take other perspectives is believed to reduce antisocial behaviour and foster empathy, sympathy, and prosocial behaviour (Spinrad & Eisenberg, 2017). A study by Aldridge and Becker (2003) has demonstrated that children differentiated between the performance of adult-oriented care tasks and the relationship they had with their parents, even when the parents were mentally ill. The children contributed due to their desire to help their parents and not in terms of 'parental child', 'parent-child role-confusion', or in terms of parentification as described by Chase

(1999), namely as behaviours transmitted between generations, where children and parents are committed to reciprocally receive care from each other. Aldridge and Becker's (2003) study has demonstrated that the children realised that there were periods when parents could not perform their parenting duties as per normal because of deteriorations in their mental health.

Different ways to research and assess children's caregiving within the research paradigms

Emotional care was in this thesis and included papers (I-III) assessed by questions of the children's provision of keeping the ill parent with company, keep an eye on the ill parent to make sure they are alright, or take the ill parent out to for a walk or to see friends or relatives (see paper I, table 2). Emotional care may also be assessed by parentification measurements such as the US' Parentification Questionnaire – Youth (PQ-Y) (Godsall et al., 2004). PQ-Y is the only validated measure for retrospective experiences of caregiving in the family for children under the age of 18, but seldom been used in research (Van Loon et al., 2017). The measure with 21 items includes three subscales of perceived fairness, instrumental- and emotional parentification. Examples of the PQ-Y items in the perceived fairness scale are 'My parents often criticized my efforts to help out at home' and 'My parents often tried to get me to take their sides of conflicts'. In the emotional care sub-scale we found items such as 'It seemed like my family members were always bringing me their problems", 'In my family I often made sacrifices that went unnoticed', and 'I often felt more like an adult than a child in my family'. In the PQ-Y instrumental scale one example is the item 'My parents expected me to help discipline my siblings'. The PQ-Y items may be understood as retrospective negative experiences of caregiving caused by their parents' negative behaviour or parenting style or as a measurement of lack of good social skills among parents via their adult children. Items in young carers measurement, such as MACA and PANOC (Joseph et al., 2009), YACS and YCOPI (Ireland & Pakenham, 2010a; Pakenham et al., 2006), YC-QST-20 (Young Carers Research Group), and YCPSS (Early et al., 2006), assess caring activities prospective in a neutral way while focusing on benefits of caregiving and stress due to their (and their families') unmet needs (Aldridge & Becker, 2003; Cassidy & Giles, 2013; Cheesbrough et al., 2017). Difference in measuring parentified children versus young carers may reflect the importance of being aware of cultural norms for caregiving, as pointed out by Aldridge and Becker (2003), Jurkovic and colleagues (2004), Pedersen and Revenson(2005), and Dai and Wang (2015).

The concept, measurement, and previous research of parentification have since the late 1990s and until now been criticised for having rarely used prospective investigation that relies on children as informants (Aldridge & Becker, 2003; Barnett & Parker, 1998; Early et al., 2006; East, 2010; Godsall et al., 2004; Haxhe, 2016; Hooper, Doehler, Wallace, & Hannah, 2011; Macfie et al., 2015; Van Loon et al., 2017). The concept role-confusion in parent-child relationships has been criticised for rarely having been explored prospectively with mothers as informants (Vulliez-Coady et al., 2013; 2016).

Children's caregiving for severely ill parents – attachment disorder or normative behaviour

A Norwegian study of children's care and domestic work at home indicated that children's contribution at home derived from a generalised socially constructed image of what mothers and fathers do (Nilsen & Wærdahl, 2015). Children adopted what appeared to be normative behaviour. Helping parents is a valuable process for learning and socialising and likely to be motivated by adult members in the family (Bruckauf & Rees, 2017). Social responsibility and moral agency in terms of prosocial behaviour provide the children with well-being and the feeling of being a good person (Fattore et al., 2012). Prosocial behaviour is associated with subjective well-being (Holte et al., 2014; Spinrad & Eisenberg, 2017; Weinstein & Ryan, 2010). However, the western culture is characterised by the normative point of view of that children should be the recipients of care, have time for friends and that knowledge and skills should be learned in situations where others do not depend on the children's provision of care (Haugland, 2006). However, families' and children's expectations of the level of children's emotional and instrumental contributions in the family and at home, in general and during parental illness, may also be influenced by cultural norms (Pedersen & Revenson, 2005; Rolland, 1999). One study found that when children have concerns about their parents' health and well-being one way of coping was to take on caring activities (Backett-Milburn & Jackson, 2012). However, the children's fear of being removed from their families was the main deterrent to help-seeking. The fear of being removed from their families is in line with findings in other studies (Aldridge & Becker, 2003; Haugland, 2006). A challenge may be when child welfare services, such as child protection, rely on 'older' parentification family therapy literature based on a selected population in therapy as adults due to parental substance abuse in their childhood.

The paradox of the welfare state and the children's quality of life as caregivers

It might be that the cultural norms for children's helping behaviour within the Norwegian welfare state, particularly child protection services, is influenced by stricter norms of normative behaviour than what may be considered normal adjustment during parental illness or substance abuse.

Several Norwegian studies have recently demonstrated that there has been limited interaction between specialised health services and community health services to ensure the needs of CAPI, partly due to the challenges of implementing the changes in the amendment to the Health Care Act (Halsa, 2018; Lauritzen, Reedtz, Van Doesum, & Martinussen, 2014; Martinsen, Weimand, Pedersen, & Norvoll, 2017; Reedtz, Lauritzen, & van Doesum, 2012; Ruud et al., 2015; Selbekk, Adams, & Sagvaag, 2018; Skogøy, Maybery, et al., 2018; Skogøy, Sorgaard, et al., 2018; Wangensteen, Bramness, & Halsa, 2018; Wiig, Halsa, Bramness, Myra, & Haugland, 2018). A previous report from the Norwegian Directorate of Health (E. K. Kallander, Brodahl, & Kibsgård, 2012) has demonstrated that if there were any interactions between the services to secure the needs of CAPI, the primary referrals were to the child welfare service. In this report, the health personnel in both community and specialised services rated child welfare services to be the primary point of referral when children needed follow-up and respite because their parents were too ill to take care of their needs as children, next-of-kin, or young carers (E. K. Kallander et al., 2012). However, instead of child protection, qualitative studies of young carers have reported that the best way services could help them were sufficient health services and support for their parents and for themselves; this came in the form of adequate information regarding care; respite and emotional support for balancing school, everyday life, and caring activities (Aldridge, 2017; Bjorgvinsdottir & Halldorsdottir, 2014; De Roos et al., 2017; Hamilton & Adamson, 2013; Hamilton & Cass, 2017; Kavanaugh, Noh, & Studer, 2015; Lackey & Gates, 2001; Metzing-Blau & Schnepp, 2008; Moore & McArthur, 2007; Rose & Cohen, 2010; Warren, 2006).

Several qualitative international studies have demonstrated that children's caregiving for an ill parent has not been recognised or acknowledged by neither the health personnel, nor the parents or the children, because of fear of child welfare services such as child protection (Aeyelts et al., 2016; Aldridge, 2017; Aldridge & Becker, 2003; Backett-Milburn & Jackson, 2012; Backett-Milburn et al., 2008; Bjorgvinsdottir & Halldorsdottir, 2014; Gray, Robinson, & Seddon, 2007; Nicholson & Friesen, 2014). A review of support interventions for children who have parents with severe physical illness has demonstrated that most support interventions aimed to enhance family functioning by helping parents to communicate with the children; the review also demonstrated that few evaluation studies used effect measures to assess children's care burdens, school achievement, and improved social support (Järkestig-Berggren & Hanson, 2016).

Within the literature on Norwegian child welfare services, children's caregiving in families with mental illness and substance abuse issues is framed within the concept of destructive parentification as well as attachment and relation disorders (Amble & Dahl-Johansen, 2016; Kvello, 2010; NOU 2009: 8; NOU 2012: 5). The Ministry of Children and Equality (NOU 2009: 8; NOU 2012: 5) has described children's caregiving for parents with mental illness and substance abuse to be parentification, and one significant factor for considering out-of-home placement, also for considering separate out-of-home placement for siblings (Falch-Eriksen, 2017). The parentification described in the governmental documents is based on the 'older' literature and are widely used and implemented assessment methods of the child welfare services, e.g.Kvello (2010); Lauritzen, Vis, Havnen, and Fossum (2017).

Children's reports of more caregiving for physically ill parents have seldom been mentioned in governmental publications or child welfare literature.

The Norwegian Directorate for Children, Youth, and Family Affairs (2011) and the Ministry of Children and Equality have developed a handbook and two films for child welfare services to inform children in school about the service's work. The films 'Alex' and 'Sara' are about an adolescent boy caring for a depressed father and a young girl caring for her mother with substance abuse issues. The message of both films is that caregiving should not be performed by children, who may receive help from the child welfare services. The message to children exposed to the 'Alex' and 'Sara' films distributed by the Ministry of Children and Equality (2011) may increase their stress related to their efforts to cope, as well as achieve control and well-being. Children may view the films and believe their social skills, prosocial behaviour, and attempts to help their parents to be incorrect. The literature states that the children often feel that they have no choice due to a lack of access to other informal or formal external care (Rose & Cohen, 2010). Järkestig-Berggren and colleagues (2018) have pointed out that the protective welfare state paradoxically conceals the experiences of children who assume caring activities. Similar to the Swedish welfare state, Norway protects children from any kind of child labour. Moreover, Järkestig-Berggren and colleagues (2018) have argued that the idea of a comprehensive and protective welfare system may conceal the impact of deinstitutionalisation and the fragmentations of support systems; examples of impacts include the family being reintroduced as the entity that is primarily responsible for supporting adult persons with various kinds of needs (Bergman, 2016; Trondsen & Tjora, 2014). This may also be the case in Norway.

The lack of governmental recognition of Norwegian young carers in the development of national research, interventions, policies, and guidelines for carer support may have a negative impact on national QoL. Children having strong social skills has been associated with a greater extent of caregiving, more positive outcomes from caregiving (papers I and II), and higher QoL (paper III). However, our findings also indicate that the parents' reports of poor physical health and the children's reports of high amount of time spent on caregiving and negative outcomes from that caregiving are associated with lower QoL in children (paper III). The difference between adult carers and young adult or young carers is that the latter are more vulnerable because they are in a developmental phase and must progress educationally to prevent dropping out or developing poor academic skills (Stamatopoulos, 2018).

However, the papers included in this thesis did not include data on the children's academic achievement. A recent qualitative study has demonstrated that the benefits from providing care were outweighed by the disadvantages associated with providing care, such as the children's social and emotional well-being, academic achievement, and not being able to take on limited part-time work (Stamatopoulos, 2018). Based on this research, Stamatapoulos (2018) has described a form of 'young carer penalty', which builds on the gendered 'care penalty' experienced by adult women (especially mothers) when performing care work. This penalty holds the carer back from pursuing educational opportunities and employment.

In 2007, the Norwegian Directorate of Health and Care Services recommended that children who assumed extensive caring activities for parents with mental illness or substance abuse problems be referred to home-based services for practical help (Sosial- og helsedirektoratet, 2007). This recommendation contradicts the recommendation of the Norwegian Ministry of Children and Equality that child protection be used as an intervention. However, 10 years later and in contrast to other countries' legislation, strategies, policies, and guidelines for carer support (Cheesbrough et al., 2017; Clay et al., 2016; Hamilton & Cass, 2017; Scottish Government, 2010, 2017; Smyth et al., 2011), the Norwegian Directorate of Health (2018) has presented a guideline for carer support that did not include 'children who conduct extensive care' in their definition of 'extensive care'. This means that these children will not have the legal rights to carer support. There is substantial international and governmental research that has demonstrated that children's unpaid care for the ill, disabled, and elderly has consequences for their academic achievement and chances at higher education (Aldridge, 2017; Cheesbrough et al., 2017; Clay et al., 2016; Hamilton & Adamson, 2013; Hamilton & Cass, 2017; Scottish Government, 2010, 2017; Smyth et al., 2011). This research has not been considered by the Norwegian Ministries of Health and Care Services, Children and Equality, or Education and Research.

To summarise; one possible 'young carer penalty' in Norway might be the threat of family disruption from child welfare services. Another Norwegian 'young carer penalty' may be how extensive care may affect academic achievement, although this was out of the scope for this doctoral thesis. Children may in the same way as adult carers; need support, guidance, and respite to achieve the same possibilities as the general population at school or work.

5.3 Conclusions and implications for practice

The first paper reports that children of a parent with a physical or mental illness or substance abuse problem perform more caring activities than children in general. The parents reported limited access to formal external care. More than two of ten parents with physical or mental illness reported that their children provided increased caring activities due to parental illness, particularly personal care. Parents with substance abuse reported rarely that their children provided increased caring activities due to parental substance abuse. The extent of children's caring activities did not differ between the parental illness groups, except that the children reported more emotional care for the parent if the parent had a physical illness than if the parent had a mental illness. Twenty-one percent of the children were making sure that the ill parent took their medicines. Extent of the children’s caring activities were negatively associated with parents’ self-reported physical health status and positively associated with the children’s self-reported social skills and external locus of control. The nature of caring activities was associated with several factors reported by the children (the children’s gender, age, social skills and external locus of control) and several factors reported by the ill parent (type of illness, parental physical health status and family income).

The second paper reports that the majority of the children reported positive outcomes from providing care. However, nearly half of the children reported stress, while 10% reported negative outcomes at a clinical level of concern. Neither positive nor negative outcomes differed between the children in the three parental illness groups. Positive outcomes were positively associated with the children’s self-reported social skills, and negatively associated with provision of household management and personal care. Negative outcomes were positively associated with the children’s self-reported external locus of control, provision of financial and practical management and personal care. Moreover, negative outcomes were negatively associated with social skills.

The third paper reports that the children’s self-reported QoL was positively associated with the ill parent’s self-reported physical health status, being a boy, the children’s self-reported social skills, that other adults take over the responsibilities for the ill parents, provision of health care for the ill parent, and positive outcome of the caregiving. QoL was negatively associated with children’s age, self-reported increased responsibilities due to parental illness, provision of emotional care, negative outcome of caregiving and external locus of control.

Across the three papers four factors seems to be particularly important for the children when parents are ill. The first, children’s self-report of good social skills, was associated with both that they reported more caregiving, more positive outcomes of their caregiving, and better QoL. The second, children’s self-report of more external locus of control, was associated with both that they reported more caregiving, more negative outcomes of caregiving, and reduced QoL. The third, ill parent’s report of reduced physical health status was associated with both that the children reported more caregiving, and reduced QoL. The fourth, the children’s negative outcome of caregiving was associated with reduced QoL, while positive outcome of caregiving was associated with increased QoL.

We found that the children affected by parental illness or parental substance abuse perform more caregiving at home and for their parent than other children do. More than half of the children experienced more responsibilities at home due to parental illness and two thirds for children of parents with physical illness. One third reported to experience too much responsibility due to parental illness. Poorer QoL was associated with older age of the children, being a girl, that the child reported more responsibility due to parental illness, and more negative outcomes of their caregiving. Better QoL was associated with the child experiencing that other adults took over the responsibilities that the ill parent usually had, the child reported provision of health care to the ill parent and more positive outcomes of caregiving.

Our results suggest that professionals within the health and child protection services should provide a more comprehensive assessment of the needs of the parents and children, regardless of the type of parental illness (i.e. physical, mental or substance abuse). Furthermore, this should include whether the parents' physical health status may negatively influence their ability to perform daily activities. Our findings also suggest that interventions to meet both the children's and families' reports of unmet needs and to reduce the children's negative outcome of increased responsibilities are particularly important and should thereby be developed and tested. In addition, the professionals within the health and child protection services should recognize the children's social skills, that their contributions at home and in the family are important and the positive impacts that children's caregiving may have on their QoL. In addition, these professionals need to be aware of and prevent the potential negative outcomes for the children. Our findings suggest that assessment of QoL could identify children who struggle the most with parental illness or parental substance abuse. The findings suggest that young Norwegian carers need the same legal rights to professional information, respite and carer support as adult carers have. These entitlements are especially important because children are more developmentally vulnerable and need to be secured their school achievements and education. The findings across the three papers indicate a prevalence of 10-12% young carers who conducted extensive care based on the Norwegian Directorate of Health definition for adult carers with extensive care and the right to carers support.

This is a large study with a broad inclusion of participants across Norway, which included children as informants and used well-established measures. There were several challenges related to recruitment that may have led to a biased sample of children affected by parental illness in this study. However, most probably the situation of the families, the extent and outcome of caring activities conducted by the children and their QoL are less positive than the study suggests.

5.4 Suggestions for future research

To estimate the prevalence of young carers there may be a need to assess the impact of caregiving as well as the extent, nature, and hours spent on caregiving. The study's findings support the need to further explore how different types of caring activities and factors may impact caregiving outcomes.

There is a special need to research children's feelings of control and social skills to identify triggers for negative outcomes. Explorations of caregiving and associations with attachment should take the form of prospective studies with a multi-informant design that includes children as informants. The varieties of findings in different samples indicate a need for representative samples and sub-samples. Findings in previous research on children's caregiving combined with our study findings support the need for national research that explores structural factors that may improve the outcomes for children who provide extensive and inappropriate caring for their ill parents.

Norwegian research and awareness of young carers is in its infancy, and available national datasets must be examined in relation to the provision of unpaid caregiving by children. Children's provision of unpaid care should be included in future Norwegian Statistics of living conditions and health. Important areas of research include the assessment of the young carers' situation, the young carers' abilities to maintain the care situation over time, and the young carers' abilities to achieve at school, enter higher education or part-time work. The children's caregiving and their families' unmet needs should be further explored in relation to access to informal and formal external care, access to health care, and access to carer support in terms of information, guidance, support, and respite. The discrepancy between interventions for adult carers and young carers in Norway should further be explored in relation to the UN Convention on the Rights of the Child.

References

Aamotsmo, T., & Bugge, K. E. (2014). Balance artistry: the healthy parent's role in the family when the other parent is in the palliative phase of cancer-challenges and coping in parenting young children. *Palliative & Supportive Care, 12*(4), 317-329. doi:10.1017/S1478951513000953

Abelsen, B., Gaski, M., Nødland, S. I., & Stephansen, A. (2014). *Samhandlingsreformens konsekvenser for det kommunale pleie- og omsorgstilbudet. Rapport IRIS - 2014/382.* . Retrieved from Stavanger: http://www.iris.no/publications/414551636/2014-382

Aeyelts, R., Marshall, S., Charles, G., & Young, R. (2016). How care is negotiated between a young carer and a parent experiencing mental illness and addiction. *International Journal of Child Youth & Family Studies, 7*(1), 65-80. doi:10.18357/ijcyfs.71201615417

Afzelius, M., Plantin, L., & Ostman, M. (2018). Families living with parental mental illness and their experiences of family interventions. *Journal of Psychiatric and Mental Health Nursing, 25*(2), 69-77. doi:10.1111/jpm.12433

Ahlstrom, B. H., Skarsater, I., & Danielson, E. (2007). Major depression in a family: what happens and how to manage - a case study. *Issues in Mental Health Nursing, 28*(7), 691-706. doi:10.1080/01612840701416023

Ahlstrom, B. H., Skarsater, I., & Danielson, E. (2009). Living with major depression: experiences from families' perspectives. *Scandinavian Journal of Caring Sciences, 23*(2), 309-316. doi:10.1111/j.1471-6712.2008.00624.x

Aldridge, J. (2006). The experiences of children living with and caring for parents with mental illness. *Child Abuse Review, 15*(2), 79-88. doi:10.1002/car.904

Aldridge, J. (2008). All Work and no Play? Understanding the Needs of Children with Caring Responsibilities. *Children & Society, 22*(4), 253-264. doi:10.1111/j.1099-0860.2007.00094.x

Aldridge, J. (2017). Where are we now? Twenty-five years of research, policy and practice on young carers. *Critical Social Policy, 38*(1), 155-165. doi:10.1177/0261018317724525

Aldridge, J., & Becker, S. (1999). Children as carers: the impact of parental illness and disability on children's caring roles. *Journal of Family Therapy, 21*(3), 303-320. doi:10.1111/1467-6427.00121

Aldridge, J., & Becker, S. (2003). *Children caring for parents with mental illness: Perspectives of young carers, parents and professionals*. Bristol: The Policy Press.

Alexanderson, K., & Näsman, E. (2016). Children’s experiences of the role of the other parent when one parent has addiction problems. *Drugs: Education, Prevention and Policy, 24*(1), 32-39. doi:10.1080/09687637.2016.1218824

Ali, L., Ahlstrom, B. H., Krevers, B., Sjostrom, N., & Skarsater, I. (2013). Support for young informal carers of persons with mental illness: a mixed-method study. *Issues in Mental Health Nursing, 34*(8), 611-618. doi:10.3109/01612840.2013.791736

Altman, D. G. (1990). *Practical statistics for medical research*: CRC press.

Amble, L., & Dahl-Johansen, C. (2016). *Miljøterapi som behandling ved komplekse traumer hos barn og unge* Oslo: Universitetsforlaget.

Andersen, J. R., Natvig, G. K., Haraldstad, K., Skrede, T., Aadland, E., & Resaland, G. K. (2016). Psychometric properties of the Norwegian version of the Kidscreen-27 questionnaire. *Health and Quality of Life Outcomes, 14*(1), 58. doi:10.1186/s12955-016-0460-4

Armstrong-Carter, E., Ivory, S., Lin, L. C., Muscatell, K. A., & Telzer, E. H. (2019). Role fulfillment mediates the association between daily family assistance and cortisol awakening response in adolescents. *Child Development*, 1-15. doi:10.1111/cdev.13213

Armstrong-Carter, E., Olson, E., & Telzer, E. (2019). A unifying approach for investigating and understanding youth's help and care for the family. *Child Development Perspectives*. doi:10.1111/cdep.12336

Axford, N., Jodrell, D., & Hobbs, T. (2014). Objective or subjective well-being? In A. Ben-Arieh, F. Casas, I. Frønes, & J. E. Korbin (Eds.), *Handbook of Child Well-Being.* (pp. 2699-2738): Springer, Dordrecht

Backe-Hansen, E., & Frønes, I. (2012). *Metoder og perspektiver i barne-og ungdomsforskning* Oslo: Gyldendal akademisk.

Backett-Milburn, K., & Jackson, S. (2012). Children's concerns about their parents' health and well-being: Researching with ChildLine Scotland. *Children & Society, 26*(5), 381-393. doi:10.1111/j.1099-0860.2010.00349.x

Backett-Milburn, K., Wilson, S., Bancroft, A., & Cunningham-Burley, S. (2008). Challenging Childhoods: Young people's accounts of `getting by' in families with substance use problems. *Childhood, 15*(4), 461-479. doi:10.1177/0907568208097202

Barne- ungdoms- og familiedirektoratet, T. N. D. f. C., Youth and Family Affairs]. (2011). *Sara & Alex. En håndbok og to filmer om barnevern til bruk i skolen [The Norwegian Directorate for Children, Youth and Family Affairs]*. Oslo: Barne-, ungdoms- og familiedirektoratet Retrieved from https://www.bufdir.no/bibliotek/Dokumentside/?docId=BUF00003158.

Barnett, B., & Parker, G. (1998). The parentified child: early competence or childhood deprivation? *Child Psychology and Psychiatry Review, 3*(4), 146-155.

Barstad, A., Normann, T. M., Nes, R. B., Reneflot, A., Røysamb, E., Hougen, H. C., . . . Herheim, Å. (2016). *Gode liv i Norge. Utredning og måling av befolkningens livskvalitet [The Norwegian Directorate of Health]*. (Rapport IS-2479). Oslo Retrieved from https://helsedirektoratet.no/publikasjoner/gode-liv-i-norge-utredning-om-maling-av-befolkningens-livskvalitet.

Bauman, L. J., Foster, G., Silver, E. J., Berman, R., Gamble, I., & Muchaneta, L. (2006). Children caring for their ill parents with HIV/AIDS. *Vulnerable Children and Youth Studies, 1*(1), 56-70. doi:10.1080/17450120600659077

Beardslee, W. R., Gladstone, T. R. G., & O'Connor, E. E. (2011). Transmission and prevention of mood disorders among children of affectively ill parents: a review. *Journal of the American Academy of Child and Adolescent Psychiatry, 50*(11), 1098-1109.

Beardslee, W. R., Versage, E. M., & Giadstone, T. R. G. (1998). Children of affectively ill parents: A review of the past 10 years. *Journal of the American Academy of Child and Adolescent Psychiatry, 37*(11), 1134-1141.

Becker, F., & Becker, S. (2008). Yong adult carers in the UK. Experiences, needs and services for carers aged 16-24. Retrieved from http://static.carers.org/files/yac20report-final-241008-3787.pdf

Becker, S. (2007). Global perspectives on children's unpaid caregiving in the family: Research and policy on 'Young Carers' in the UK, Australia, the USA and Sub-Saharan Africa. *Global Social Policy, 7*(1), 23-50. doi:10.1177/1468018107073892

Becker, S., & Sempik, J. (2018). Young Adult Carers: the impact of caring on health and education. *Children & Society*. doi:10.1111/chso.12310

Bee, P., Berzins, K., Calam, R., Pryjmachuk, S., & Abel, K. M. (2013). Defining quality of life in the children of parents with severe mental illness: a preliminary stakeholder-led model. *PloS One, 8*(9), e73739. doi:10.1371/journal.pone.0073739

Beierlein, V., Bultmann, J. C., Moller, B., von Klitzing, K., Flechtner, H. H., Resch, F., . . . Bergelt, C. (2017). Measuring family functioning in families with parental cancer: reliability and validity of the German adaptation of the Family Assessment Device (FAD). *Journal of Psychosomatic Research, 93*, 110-117. doi:10.1016/j.jpsychores.2016.11.007

Ben-Arieh, A., Casas, F., Frønes, I., & Korbin, J. E. (2014). Multifaceted concept of child well-being. In A. Ben-Arieh, F. Casas, I. Frønes, & J. E. Korbin (Eds.), *Handbook of child well-being* (pp. 1-27): Springer, Dordrecht

Ben-Arieh, A., & Frønes, I. (2006). Indicators of children’s well being - concepts, indices and usage. *Social Indicators Research, 80*(1), 1-4. doi:10.1007/s11205-006-9069-z

Ben-Arieh, A., & Frønes, I. (2007). Indicators of children’s well being: what should be measured and why? *Social Indicators Research, 84*(3), 249-250. doi:10.1007/s11205-007-9183-6

Berg-Hansen, P., Moen, S. M., Harbo, H. F., & Celius, E. G. (2014). High prevalence and no latitude gradient of multiple sclerosis in Norway. *Multiple Sclerosis Journal, 20*(13), 1780-1782. doi:10.1177/1352458514525871

Berg-Nielsen, T. S., Solheim, E., Belsky, J., & Wichstrom, L. (2012). Preschoolers' psychosocial problems: in the eyes of the beholder? Adding teacher characteristics as determinants of discrepant parent-teacher reports. *Child Psychiatry and Human Development, 43*(3), 393-413. doi:10.1007/s10578-011-0271-0

Berg-Nielsen, T. S., Vika, A., & Dahl, A. A. (2003). When adolescents disagree with their mothers: CBCL-YSR discrepancies related to maternal depression and adolescent self-esteem. *Child: Care, Health and Development, 29*(3), 207-213.

Bergman, A. S. (2016). “In a Proper Home” Foster Children’s Needs and Foster Parents’ Suitability during the Twentieth Century. *Journal of Family History, 41*(2), 176-191. doi:10.1177/0363199016635493

Berman, A. H., Liu, B., Ullman, S., Jadback, I., & Engstrom, K. (2016). Children's quality of life based on the KIDSCREEN-27: child self-report, parent ratings and child-parent agreement in a Swedish random population sample. *PloS One, 11*(3), 1-15. doi:10.1371/journal.pone.0150545

Birkeland, B., Weimand, B. M., Ruud, T., Hoie, M. M., & Vederhus, J. K. (2017). Perceived quality of life in partners of patients undergoing treatment in somatic health, mental health, or substance use disorder units: a cross-sectional study. *Health and Quality of Life Outcomes, 15*(1), 172. doi:10.1186/s12955-017-0750-5

Bisegger, C., Cloetta, B., von Rueden, U., Abel, T., Ravens-Sieberer, U., & the European KIDSCREEN Group. (2005). Health-related quality of life: gender differences in childhood and adolescence. *Sozial- und Praventivmedizin, 50*(5), 281-291. doi:10.1007/s00038-005-4094-2

Bjorgvinsdottir, K., & Halldorsdottir, S. (2014). Silent, invisible and unacknowledged: experiences of young caregivers of single parents diagnosed with multiple sclerosis. *Scandinavian Journal of Caring Sciences, 28*(1), 38-48. doi:10.1111/scs.12030

Boeschoten, R. E., Braamse, A. M. J., Beekman, A. T. F., Cuijpers, P., van Oppen, P., Dekker, J., & Uitdehaag, B. M. J. (2017). Prevalence of depression and anxiety in Multiple Sclerosis: A systematic review and meta-analysis. *Journal of the Neurological Sciences, 372*, 331-341. doi:10.1016/j.jns.2016.11.067

Bogosian, A., Moss-Morris, R., Bishop, F. L., & Hadwin, J. (2011). How do adolescents adjust to their parent's multiple sclerosis? An interview study. *British Journal of Health Psychology, 16*(2), 430-444. doi:10.1348/135910710X521492

Bogosian, A., Moss-Morris, R., Bishop, F. L., & Hadwin, J. (2014). Development and initial validation of the Perceptions of Parental Illness Questionnaire. *Journal of Health Psychology, 19*(7), 931-942. doi:10.1177/1359105313482164

Borgan, J. K. (2012, Mars 2012). Pleie- og omsorgsstatistikk 1962-2010 [Statistics Norway]. *Rapporter 10/2012* Retrieved from https://www.ssb.no/a/publikasjoner/pdf/rapp_201210/rapp_201210.pdf

Boszormenyi-Nagy, I., & Krasner, B. (1986). *Between give and take: A clinical guide to contextual therapy*. New York: Brunner Mazel.

Boszormenyi-Nagy, I., & Spark, G. (1973). *Invisible loyalties*. New York: Harper and Row.

Boumans, N. P. G., & Dorant, E. (2018). A cross-sectional study on experiences of young adult carers compared to young adult noncarers: parentification, coping and resilience. *Scandinavian Journal of Caring Sciences, 32*(4), 1409-1417. doi:10.1111/scs.12586

Bowlby, J. (1977). The making and breaking of affectional bonds. I. Aetiology and psychopathology in the light of attachment theory. An expanded version of the Fiftieth Maudsley Lecture, delivered before the Royal College of Psychiatrists, 19 November 1976. *British Journal of Psychiatry, 130*(3), 201-210.

Bradshaw, J., Keung, A., Rees, G., & Goswami, H. (2011). Children's subjective well-being: International comparative perspectives. *Children and Youth Services Review, 33*(4), 548-556. doi:10.1016/j.childyouth.2010.05.010

Brattheim, B. J., Hellesø, R., & Melby, L. (2016). Elektronisk meldingsutveksling ved utskrivning av pasienter fra sykehus til kommune. *Sykepleien Forskning, 11*(3), 26-33. doi:10.4220/Sykepleienf.2016.56830

Bronfenbrenner, U. (1977). Toward an Experimental Ecology of Human-Development. *American Psychologist, 32*(7), 513-531. doi:10.1037/0003-066x.32.7.513

Bronfenbrenner, U., & Morris, P. A. (1998). The ecology of developmental processes. In W. Damon & R. M. Lerner (Eds.), *Handbook of child psychology: Theoretical models of human development (pp. 993-1028)*. Hoboken, NJ, US: John Wiley & Sons Inc

Bruckauf, Z., & Rees, G. (2017). Children’s participation in housework: Is there a case of gender stereotyping? *Evidence from the International Survey of Children's' Well-Being (ISCWeB), UNICEF Office of Research Innocenti Research Brief.* Retrieved from https://www.unicef-irc.org/publications/898-childrens-involvement-in-housework-is-there-a-case-of-gender-stereotyping-evidence.html

Bultmann, J. C., Beierlein, V., Romer, G., Moller, B., Koch, U., & Bergelt, C. (2014). Parental cancer: Health-related quality of life and current psychosocial support needs of cancer survivors and their children. *International Journal of Cancer, 135*(11), 2668-2677. doi:10.1002/ijc.28905

Burnett, G., Jones, R. A., Bliwise, N. G., & Ross, L. T. (2006). Family unpredictability, parental alcoholism, and the development of parentification. *American Journal of Family Therapy, 34*(3), 181-189. doi:10.1080/01926180600550437

Byng-Hall, J. (2002). Relieving parentified children's burdens in families with insecure attachment patterns. *Family Process, 41*(3), 375-388.

Camfield, L., Crivello, G., & Woodhead, M. (2009). Wellbeing research in developing countries: Reviewing the role of qualitative methods. *Social Indicators Research, 90*(1), 5-31. doi:10.1007/s11205-008-9310-z

Casas, F. (2011). Subjective social indicators and child and adolescent well-being. *Child Indicators Research, 4*(4), 555-575. doi:10.1007/s12187-010-9093-z

Casas, F., Coenders, G., Cummins, R. A., González, M., Figuer, C., & Malo, S. (2008). Does subjective well-being show a relationship between parents and their children? *Journal of Happiness Studies, 9*(2), 197-205. doi:10.1007/s10902-007-9044-7

Cassidy, T., & Giles, M. (2013). Further exploration of the Young Carers Perceived Stress Scale: identifying a benefit-finding dimension. *British Journal of Health Psychology, 18*(3), 642-655. doi:10.1111/bjhp.12017

Cassidy, T., Giles, M., & McLaughlin, M. (2014). Benefit finding and resilience in child caregivers. *British Journal of Health Psychology, 19*(3), 606-618. doi:10.1111/bjhp.12059

Champion, J. E., Jaser, S. S., Reeslund, K. L., Simmons, L., Potts, J. E., Shears, A. R., & Compas, B. E. (2009). Caretaking behaviors by adolescent children of mothers with and without a history of depression. *Journal of Family Psychology, 23*(2), 156-166. doi:10.1037/a0014978

Chase, N. D. (1999). *Burdened children: Theory, research, and treatment of parentification*. Thousand Oaks: Sage Publication.

Chase, N. D., Deming, M. P., & Wells, M. C. (1998). Parentification, parental alcoholism, and academic status among young adults. *American Journal of Family Therapy, 26*(2), 105-114. doi:10.1080/01926189808251091

Cheesbrough, S., Harding, C., Webster, L., & Aldridge, J. (2017). *The lives of young carers in England: Omnibus survey report*. London: Department for Education Retrieved from https://www.gov.uk/government/publications/the-lives-of-young-carers-in-england.

Chikhradze, N., Knecht, C., & Metzing, S. (2017). Young carers: growing up with chronic illness in the family - a systematic review 2007-2017. *Journal of Compassionate Health Care, 4*(1), 12. doi:10.1186/s40639-017-0041-3

Christensen, P., & James, A. (2008). *Research with children: Perspectives and practices* (2 ed.). London: Routledge.

Clay, D., Connors, C., Day, N., Gkiza, M., & Aldridge, J. (2016). *The lives of young carers in England. Qualitative report to Dfe*. London: Department of Education Retrieved from https://www.gov.uk/government/publications/the-lives-of-young-carers-in-england.

Cleaver, H., Unell, I., & Aldgate, J. (2011). *Children's needs -parenting capacity: child abuse, parental mental illness, learning disability, substance misuse, and domestic violence (2nd edition)*. London: The Stationery Office.

Clifford, G., & Øyen, L. (2018). Tiltaksprofil og tiltaksutvikling i kommunalt barnevern In E. Marthinsen & W. Lichtwarck (Eds.), *Det nye barnevernet* (pp. 87-113). Oslo: Universitetsforlaget.

Cohen, S. (2008). Basic psychometrics for the ISEL-12. Retrieved from http://www.psy.cmu.edu/~scohen/scales.html

Cohen, S., & Hoberman, H. M. (1983). Positive events and social supports as buffers of life change stress. *Journal of Applied Social Psychology, 13*(2), 99-125. doi:10.1111/j.1559-1816.1983.tb02325.x

Coker, T. R., Elliott, M. N., Wallander, J. L., Cuccaro, P., Grunbaum, J. A., Corona, R., . . . Schuster, M. A. (2011). Association of family stressful life-change events and health-related quality of life in fifth-grade children. *Archives of Pediatrics and Adolescent Medicine, 165*(4), 354-359. doi:10.1001/archpediatrics.2011.13

Comiskey, C. M., Milnes, J., & Daly, M. (2017). Parents who use drugs: the well-being of parent and child dyads among people receiving harm reduction interventions for opiate use. *Journal of Substance Use, 22*(2), 206-210. doi:10.1080/14659891.2016.1177616

Cox, S. D., & Pakenham, K. I. (2014). Confirmatory factor analysis and invariance testing of the Young Carer of Parents Inventory (YCOPI). *Rehabilitation Psychology, 59*(4), 439-452. doi:10.1037/a0035860

Cree, V. E. (2003). Worries and problems of young carers: issues for mental health *Child & Family Social Work, 8*, 301-309.

Cree, V. E., Kay, H., & Tisdall, K. (2002). Research with children: sharing the dilemmas. *Child & Family Social Work, 7*(1), 47-56.

Cuijpers, P., Weitz, E., Karyotaki, E., Garber, J., & Andersson, G. (2015). The effects of psychological treatment of maternal depression on children and parental functioning: a meta-analysis. *European Child and Adolescent Psychiatry, 24*(2), 237-245. doi:10.1007/s00787-014-0660-6

Culpin, I., Stapinski, L., Miles, O. B., Araya, R., & Joinson, C. (2015). Exposure to socioeconomic adversity in early life and risk of depression at 18 years: The mediating role of locus of control. *Journal of Affective Disorders, 183*, 269-278. doi:10.1016/j.jad.2015.05.030

Cummins, R. A. (2000). Objective and subjective quality of life: an interactive model. *Social Indicators Research, 52*(1), 55-72. doi:10.1023/A:1007027822521

Cummins, R. A. (2010). Fluency disorders and life quality: subjective wellbeing vs. health-related quality of life. *Journal of Fluency Disorders, 35*(3), 161-172. doi:10.1016/j.jfludis.2010.05.009

Dai, L., & Wang, L. (2015). Review of Family Functioning. *Open Journal of Social Sciences, 03*(12), 134-141. doi:10.4236/jss.2015.312014

Dam, K., & Hall, E. O. (2016). Navigating in an unpredictable daily life: a metasynthesis on children's experiences living with a parent with severe mental illness. *Scandinavian Journal of Caring Sciences, 30*(3), 442-457. doi:10.1111/scs.12285

De Los Reyes, A., Goodman, K. L., Kliewer, W., & Reid-Quinones, K. (2008). Whose depression relates to discrepancies? Testing relations between informant characteristics and informant discrepancies from both informants' perspectives. *Psychological Assessment, 20*(2), 139-149. doi:10.1037/1040-3590.20.2.139

De Roos, S. A., De Boer, A. H., & Bot, S. M. (2017). Well-being and need for support of adolescents with a chronically ill family member. *Journal of child and family studies, 26*(2), 405-415. doi:10.1007/s10826-016-0574-7

Dearden, C., & Becker, S. (2003). *Young carers and education*. Retrieved from London: https://www.lboro.ac.uk/microsites/socialsciences/ycrg/youngCarersDownload/yceduc%5b1%5d.pdf

Dearden, C., & Becker, S. (2004). *Young Carers Report UK 2004*. Retrieved from London: https://www.lboro.ac.uk/microsites/socialsciences/ycrg/youngCarersDownload/YCReport2004%5b1%5d.pdf

Detmar, S. B., Bruil, J., Ravens-Sieberer, U., Gosch, A., Bisegger, C., & the European KIDSCREEN Group. (2006). The use of focus groups in the development of the KIDSCREEN HRQL questionnaire. *Quality of Life Research, 15*(8), 1345-1353. doi:10.1007/s11136-006-0022-z

Diener, E., & Suh, E. (1997). Measuring quality of life: Economic, social, and subjective indicators. *Social Indicators Research, 40*(1-2), 189-216. doi:10.1023/A:1006859511756

Dittrich, K., Fuchs, A., Bermpohl, F., Meyer, J., Fuhrer, D., Reichl, C., . . . Resch, F. (2018). Effects of maternal history of depression and early life maltreatment on children's health-related quality of life. *Journal of Affective Disorders, 225*, 280-288. doi:10.1016/j.jad.2017.08.053

Earley, L., & Cushway, D. (2002). The parentified child. *Clinical Child Psychology and Psychiatry, 7*(2), 163-178.

Early, L., Cushway, D., & Cassidy, T. (2006). Perceived Stress in Young Carers: Development of a Measure. *Journal of child and family studies, 15*(2), 165-176. doi:10.1007/s10826-005-9011-z

East, P. L. (2010). Children's Provision of Family Caregiving: Benefit or Burden? *Child Development Perspectives, 4*(1), 55-61. doi:10.1111/j.1750-8606.2009.00118.x

Eisenberg, N., Cumberland, A., & Spinrad, T. L. (1998). Parental Socialization of Emotion. *Psychological Inquiry, 9*(4), 241-273. doi:10.1207/s15327965pli0904_1

Eisenberg, N., Zhou, Q., & Koller, S. (2001). Brazilian adolescents' prosocial moral judgment and behavior: relations to sympathy, perspective taking, gender-role orientation, and demographic characteristics. *Child Development, 72*(2), 518-534.

Eiser, C., & Varni, J. W. (2013). Health-related quality of life and symptom reporting: similarities and differences between children and their parents. *European Journal of Pediatrics, 172*(10), 1299-1304. doi:10.1007/s00431-013-2049-9

Elf, M., Skarsater, I., & Krevers, B. (2011). 'The web is not enough, it's a base'-an explorative study of what needs a web-based support system for young carers must meet. *Informatics for Health and Social Care, 36*(4), 206-219. doi:10.3109/17538157.2011.553298

Elsenbroich, C., & Xenitidou, M. (2012). Three kinds of normative behaviour: minimal requirements for feedback models. *Computational and Mathematical Organization Theory, 18*(1), 113-127. doi:10.1007/s10588-012-9109-y

Evans, R. (2010). Children’s caring roles and responsibilities within the family in Africa. *Geography Compass, 4*(10), 1477-1496. doi:10.1111/j.1749-8198.2010.00386.x

Evans, R. (2014). Children as caregivers. In A. Ben-Arieh, F. Casas, I. Frønes, & J. E. Korbin (Eds.), *Handbook of child well-being* (pp. 1893-1916): Springer, Dordrecht.

Evans, R., & Becker, S. (2009). *Children caring for parents with HIV and AIDS: Global issues and policy responses*. Bristol: Policy press.

Falch-Eriksen, A. (2017). *Søsken og plassering i fosterhjem. Rapport om utfordringer, hindringer og tiltak ved søskenplassering i fosterhjem*. Retrieved from Oslo:

Fattore, T., Mason, J., & Watson, E. (2006). Children’s conceptualisation(s) of their well-being. *Social Indicators Research, 80*(1), 5-29. doi:10.1007/s11205-006-9019-9

Fattore, T., Mason, J., & Watson, E. (2009). When children are asked about their well-being: towards a framework for guiding policy. *Child Indicators Research, 2*(1), 57-77. doi:10.1007/s12187-008-9025-3

Fattore, T., Mason, J., & Watson, E. (2012). Locating the child centrally as subject in research: towards a child Interpretation of well-Being. *Child Indicators Research, 5*(3), 423-435. doi:10.1007/s12187-012-9150-x

Fattore, T., Mason, J., & Watson, E. (2016). *Children’s understandings of well-being: Towards a child standpoint* (Vol. 14). Dordrecht: Springer.

Finan, L. J., Schulz, J., Gordon, M. S., & Ohannessian, C. M. (2015). Parental problem drinking and adolescent externalizing behaviors: The mediating role of family functioning. *Journal of Adolescence, 43*, 100-110. doi:10.1016/j.adolescence.2015.05.001

Forskningsrådet. (2011). Barn som pårørende (BARN) [The Research Council of Norway. Children as Relatives (BARN)]. Retrieved from https://www.forskningsradet.no/no/Utlysning/BARN/1253965557341

Foster, C. J., Garber, J., & Durlak, J. A. (2008). Current and past maternal depression, maternal interaction behaviors, and children's externalizing and internalizing symptoms. *Journal of Abnormal Child Psychology, 36*(4), 527-537. doi:10.1007/s10802-007-9197-1

Foulds, J. A., Adamson, S. J., Boden, J. M., Williman, J. A., & Mulder, R. T. (2015). Depression in patients with alcohol use disorders: Systematic review and meta-analysis of outcomes for independent and substance-induced disorders. *Journal of Affective Disorders, 185*, 47-59. doi:10.1016/j.jad.2015.06.024

Fraser, E., & Pakenham, K. I. (2009). Resilience in children of parents with mental illness: relations between mental health literacy, social connectedness and coping, and both adjustment and caregiving. *Psychology, Health & Medicine, 14*(5), 573-584. doi:10.1080/13548500903193820

Freire, T., & Ferreira, G. (2016). Health-related quality of life of adolescents: Relations with positive and negative psychological dimensions. *International Journal of Adolescence and Youth, 23*(1), 11-24. doi:10.1080/02673843.2016.1262268

Frey, J. R., Elliott, S. N., & Gresham, F. M. (2011). Preschoolers’ social skills: Advances in assessment for intervention using social behavior ratings. *School Mental Health, 3*(4), 179-190. doi:10.1007/s12310-011-9060-y

Friedlander, S., Weiss, D. S., & Traylor, J. (1986). Assessing the influence of maternal depression on the validity of the Child Behavior Checklist. *Journal of Abnormal Child Psychology, 14*(1), 123-133.

Galvin, B. M., Randel, A. E., Collins, B. J., & Johnson, R. E. (2018). Changing the focus of locus (of control): A targeted review of the locus of control literature and agenda for future research. *Journal of Organizational Behavior, 39*(7), 820-833. doi:10.1002/job.2275

Gaspar, T., Ribeiro, J. P., de Matos, M. G., Leal, I., & Ferreira, A. (2012). Health-related quality of life in children and adolescents: subjective well Being. *Spanish Journal of Psychology, 15*(1), 177-186. doi:10.5209/rev_SJOP.2012.v15.n1.37306

Giannakopoulos, G., Dimitrakaki, C., Pedeli, X., Kolaitis, G., Rotsika, V., Ravens-Sieberer, U., & Tountas, Y. (2009). Adolescents' wellbeing and functioning: relationships with parents' subjective general physical and mental health. *Health and Quality of Life Outcomes, 7*, 100. doi:10.1186/1477-7525-7-100

Gladstone, B. M., Boydell, K. M., & McKeever, P. (2006). Recasting research into children's experiences of parental mental illness: beyond risk and resilience. *Social Science and Medicine, 62*(10), 2540-2550. doi:10.1016/j.socscimed.2005.10.038

Godsall, R. E., Jurkovic, G. J., Emshoff, J., Anderson, L., & Stanwyck, D. (2004). Why some kids do well in bad situations: Relation of parental alcohol misuse and parentification to children's self-concept. *Substance Use and Misuse, 39*(5), 789-809. doi:10.1081/Ja-120034016

Gonzalez, M., Casas, F., & Coenders, G. (2007). A complexity approach to psychological well-being in adolescence: major strengths and methodological issues. *Social Indicators Research, 80*(2), 267-295. doi:10.1007/s11205-005-5073-y

Grabiak, B. R., Bender, C. M., & Puskar, K. R. (2007). The impact of parental cancer on the adolescent: an analysis of the literature. *Psycho-Oncology, 16*(2), 127-137. doi:10.1002/pon.1083

Gray, B., Robinson, C., & Seddon, D. (2007). Invisible children: Young carers of parents with mental health problems - the perspectives of professionals. *Child and Adolescent Mental Health, 13*(4), 169-172. doi:10.1111/j.1475-3588.2007.00477.x

Greenwood, N., Mezey, G., & Smith, R. (2018). Social exclusion in adult informal carers: a systematic narrative review of the experiences of informal carers of people with dementia and mental illness. *Maturitas, 112*, 39-45. doi:10.1016/j.maturitas.2018.03.011

Gresham, F. M., & Elliott, S. N. (1990a). *Social skills rating system (SSRS)*: American Guidance Service.

Gresham, F. M., & Elliott, S. N. (1990b). *Social skills rating system: Manual*: American Guidance Service.

Gresham, F. M., & Elliott, S. N. (2008). *Social Skills Improvement System: Rating Scales.* Bloomington, MN: Pearson Assessments.

Gresham, F. M., Elliott, S. N., Vance, M. J., & Cook, C. R. (2011). Comparability of the Social Skills Rating System to the Social Skills Improvement System: content and psychometric comparisons across elementary and secondary age levels. *School Psychology Quarterly, 26*(1), 27-44. doi:10.1037/a0022662

Gullbrå, F., Smith-Sivertsen, T., Rortveit, G., Anderssen, N., & Hafting, M. (2014). To give the invisible child priority: children as next of kin in general practice. *Scandinavian Journal of Primary Health Care, 32*(1), 17-23. doi:10.3109/02813432.2014.874133

Hagen, K. A., Hilsen, M., Kallander, E. K., & Ruud, T. (2018). Health-related quality of life (HRQoL) in children of ill or substance abusing parents: examining factor structure and sub-group differences. *Quality of Life Research*, 1-11. doi:10.1007/s11136-018-2067-1

Haine, R. A., Ayers, T. S., Sandler, I. N., Wolchik, S. A., & Weyer, J. L. (2003). Locus of control and self-esteem as stress-moderators or stress-mediators in parentally bereaved children. *Death Studies, 27*(7), 619-640. doi:10.1080/07481180390220807

Halsa, A. (2018). Trapped between madness and motherhood: Mothering alone. *Social Work in Mental Health, 16*(1), 46-61. doi:10.1080/15332985.2017.1317688

Hamilton, M. G., & Adamson, E. (2013). Bounded agency in young carers' lifecourse-stage domains and transitions. *Journal of Youth Studies, 16*(1), 101-117. doi:10.1080/13676261.2012.710743

Hamilton, M. G., & Cass, B. (2017). Capturing the centrality of age and life-course stage in the provision of unpaid care. *Journal of Sociology, 53*(1), 79-93. doi:10.1177/1440783315625117

Haug Fjone, H., Ytterhus, B., & Almvik, A. (2009). How children with parents suffering from mental health distress search for 'normality'and avoid stigma: to be or not to be... is not the question. *Childhood, 16*(4), 461-477. doi:10.1177/0907568209343743

Haugen, G. M. D. (2007). Caring children: exploring care in post-divorce families. *The Sociological Review, 55*(4), 653-670. doi:10.1111/j.1467-954X.2007.00743.x

Haugland, B. S. M. (2005). Recurrent disruptions of rituals and routines in families with paternal alcohol abuse. *Family Relations, 54*(2), 225-241. doi:10.1111/j.0197-6664.2005.00018.x

Haugland, B. S. M. (2006). Barn som omsorgsgivere: Adaptiv versus destruktiv parentifisering *Tidsskrift for Norsk Psykologforening, 43*(3), 211.

Hauken, M. A., Pereira, M., & Senneseth, M. (2018). The effects on children's anxiety and quality of life of a psychoeducational program for families living with parental cancer and their network: a randomized controlled trial study. *Cancer Nursing, 41*(6), 473-483. doi:10.1097/NCC.0000000000000529

Haxhe, S. (2016). Parentification and related processes: distinction and implications for clinical practice. *Journal of Family Psychotherapy, 27*(3), 185-199. doi:10.1080/08975353.2016.1199768

Helse- og omsorgsdepartementet. (2009). *Om lov om endringar i helsepersonellloven m.m. (oppfølging av born som pårørande) [The Norwegain Ministry of Health and Care Services]* (Ot.prp. nr. 84 (2008–2009)). Oslo: Helse- og omsorgsdepartementet Retrieved from https://www.regjeringen.no/contentassets/c6e80f44f6114a0a91a637c8060796ff/nn-no/pdfs/otp200820090084000dddpdfs.pdf.

Helse- og omsorgsdepartementet. (2013). *Morgendagens omsorg (Meld. St. 29 (2012–2013) [The Norwegain Ministry of Health and Care Services]* Oslo: Helse- og omsorgsdepartementet Retrieved from https://www.regjeringen.no/no/dokumenter/meld-st-29-20122013/id723252/.

Helse- og omsorgsdepartementet. (2015). *Folkehelsemeldingen — Mestring og muligheter (Meld. St. 19 2014-2015)[The Norwegian Ministry Health and Care Services]*. Oslo: Helse- og omsorgsdepartementet Retrieved from https://www.regjeringen.no/no/dokumenter/meld.-st.-19-2014-2015/id2402807/.

Helse- og omsorgsdepartementet. (2017a). *Endringer i helse- og omsorgstjenesteloven m.m. (styrket pårørendestøtte)*. (Prop. 49 L). Oslo: Helse- og omsorgsdepartementet Retrieved from https://www.regjeringen.no/no/dokumenter/prop.-49-l-20162017/id2526898/sec1.

Helse- og omsorgsdepartementet. (2017b). *Endringer i helse- og omsorgstjenesteloven m.m. (styrket pårørendestøtte) (Prop. 49 L 2016–2017) [The Norwegian Ministry Health and Care Services]*. Oslo: Helse- og omsorgsdepartementet, Retrieved from https://www.regjeringen.no/no/dokumenter/prop.-49-l-20162017/id2526898/.

Helse- og omsorgsdepartementet. (2017c). *Høringsnotat. Forslag til forskrift om barns rett til å samtykke til deltagelse i medisinske og helsefaglige forskningsprosjekter [The Norwegian Ministry Health and Care Services]*. Oslo: Helse- og omsorgsdepartementet Retrieved from https://www.regjeringen.no/contentassets/6cb21b0eefb74854b2a12a0235167960/hnotat_asd.pdf.

Helsedirektoratet. (2010). *Barn som pårørende [The Norwegain Directorate of Health]* (Rundskriv IS-5/2010). Oslo: Helsedirektoratet Retrieved from https://helsedirektoratet.no/Lists/Publikasjoner/Attachments/414/Barn-som-parorende-IS-5-2010.pdf.

Helsedirektoratet. (2015). *Well-being på norsk [The Norwegain Directorate of Health]*. (IS-2344). Oslo: Helsedirektoratet Retrieved from https://helsedirektoratet.no/Lists/Publikasjoner/Attachments/971/Well-being%20p%C3%A5%20norsk%20IS-2344.pdf.

Helsedirektoratet. (2016a). *Gode liv i Norge. Utredning om måling av befolkningens livskvalitet [The Norwegain Directorate of Health]* (Rapport IS-2479). Oslo: Helsedirektoratet Retrieved from https://helsedirektoratet.no/publikasjoner/gode-liv-i-norge-utredning-om-maling-av-befolkningens-livskvalitet.

Helsedirektoratet. (2016b). *Status for samhandlingsreformen. Forvaltningsmessig følge med-rapport fra Helsedirektoratet. Rapport IS-2893 [Norwegian Directorate of Health]*. Oslo.

Helsedirektoratet. (2017). *Program for folkehelsearbeid i kommunene 2017-2027. En satsing for å fremme barn og unges psykiske helse og livskvalitet [The Norwegain Directorate of Health]* Oslo: Helsedirektoratet Retrieved from https://helsedirektoratet.no/Documents/Folkehelsearbeid%20i%20kommunen/Program%20for%20folkehelsearbeid%20i%20kommunene%202017-2027.pdf.

Helsedirektoratet. (2018). *Veileder om pårørende i helse- og omsorgstjenesten (Guidelines for carer support in the health- and care services) [The Norwegain Directorate of Health]* (IS-2587). Oslo: Helsedirektoratet Retrieved from https://helsedirektoratet.no/Retningslinjer/P%C3%A5r%C3%B8rendeveileder.pdf.

Helsepersonelloven. (1999). Lov om helsepersonell m.v. (LOV-1999-07-02-64) [The Health Personnel Act] Retrieved from https://lovdata.no/dokument/NL/lov/1999-07-02-64

Helseth, S., Lund, T., & Christophersen, K. A. (2006). Health-related quality of life in a Norwegian sample of healthy adolescents: some psychometric properties of CHQ-CF87-N in relation to KINDL-N. *Journal of Adolescent Health, 38*(4), 416-425. doi:10.1016/j.jadohealth.2004.11.136

Heyman, A., & Heyman, B. (2013). 'The sooner you can change their life course the better': the time-framing of risks in relationship to being a young carer. *Health, Risk & Society, 15*(6-07), 561-579. doi:10.1080/13698575.2013.830080

Hjermann, R. (2007, 01.05.2007). Barnearbeid på norsk. *Aftenposten*. Retrieved from https://www.aftenposten.no/meninger/kronikk/i/y481x/Barnearbeid-pa-norsk

Holte, A., Barry, M. M., Bekkhus, M., Borge, A. I. H., Bowes, L., Casas, F., . . . Jozefiak, T. (2014). Psychology of child well-being. In A. Ben-Arieh, F. Casas, I. Frønes, & J. E. Korbin (Eds.), *Handbook of child well-being* (pp. 555-631): Springer, Dordrecht.

Hooper, L. M., Doehler, K., Wallace, S. A., & Hannah, N. J. (2011). The Parentification Inventory: development, validation, and cross-validation. *American Journal of Family Therapy, 39*(3), 226-241. doi:10.1080/01926187.2010.531652

Hudson, P., Aranda, S., Kristjanson, L., & Quinn, K. (2005). Minimising gate-keeping in palliative care research. *European Journal of Palliative Care, 12*(4), 165-169.

Huebner, E. S., Gilman, R., & Ma, C. (2012). Perceived quality of life of children and youth. In K. Land, A. Michalos, & M. Sirgy (Eds.), *Handbook of social indicators and quality of life research* (pp. 355-372): Springer, Dordrecht.

Huebner, E. S., Valois, R. F., Suldo, S. M., Smith, L. C., McKnight, C. G., Seligson, J. L., & Zullig, K. J. (2004). Perceived quality of life: a neglected component of adolescent health assessment and intervention. *Journal of Adolescent Health, 34*(4), 270-278. doi:10.1016/j.jadohealth.2003.07.007

Humphrey, N., Kalambouka, A., Wigelsworth, M., Lendrum, A., Deighton, J., & Wolpert, M. (2011). Measures of social and emotional skills for children and young people: A systematic review. *Educational and Psychological Measurement, 71*(4), 617-637. doi:10.1177/0013164410382896

Hundeide, K. (2003). *Barns livsverden: sosiokulturelle rammer for barns utvikling*. Oslo: Cappelen Akademiske forlag.

IBM, C. (2015). Released 2015. IBM SPSS Statistics for windows, Version 22.0.

Ide, B., Dingmann, C., Cuevas, E., & Meehan, M. (2010). Psychometric testing of the FACES III with rural adolescents. *Journal of Family Social Work, 13*(5), 410-419. doi:10.1080/10522150903513993

Ireland, M. J., & Pakenham, K. I. (2010a). The nature of youth care tasks in families experiencing chronic illness/disability: development of the Youth Activities of Caregiving Scale (YACS). *Psychology & Health, 25*(6), 713-731. doi:10.1080/08870440902893724

Ireland, M. J., & Pakenham, K. I. (2010b). Youth adjustment to parental illness or disability: the role of illness characteristics, caregiving, and attachment. *Psychology, Health & Medicine, 15*(6), 632-645. doi:10.1080/13548506.2010.498891

Isungset, M. A., & Lunde, S. E. (2017). Levekårsundersøkelsen om helse 2015 [Statistics Norway]. *Notater 2017/9.* Retrieved from https://www.ssb.no/sosiale-forhold-og-kriminalitet/artikler-og-publikasjoner/_attachment/293634?_ts=159f922c2d0

Jacobson, S., & Wood, F. G. (2004). Contributions of children to the care of adults with diabetes. *Diabetes Educator, 30*(5), 820-826. doi:10.1177/014572170403000517

James, A., Jenks, C., & Prout, A. (1999). *Den teoretiske barndom*. København: Socialpædagogisk bibliotek.

Jeppesen, E., Bjelland, I., Fossa, S. D., Loge, J. H., & Dahl, A. A. (2016). Health-related quality of life in teenagers with a parent with cancer. *European Journal of Oncology Nursing, 22*, 46-53. doi:10.1016/j.ejon.2016.03.004

Jeske, J., Bullinger, M., & Wiegand-Grefe, S. (2011). Do attachment patterns of parents with a mental illness have an impact upon how they view the quality of life of their children? *Vulnerable Children and Youth Studies, 6*(1), 39-50. doi:10.1080/17450128.2011.554580

Jonsson, U., Alaie, I., Lofgren Wilteus, A., Zander, E., Marschik, P. B., Coghill, D., & Bolte, S. (2017). Annual research review: Quality of life and childhood mental and behavioural disorders - a critical review of the research. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 58*(4), 439-469. doi:10.1111/jcpp.12645

Joseph, S., Becker, F., & Becker, S. (2012). *Manual for measures of caring activities and outcomes for children and young people* (2 ed.). London: Carers Trust.

Joseph, S., Becker, S., Becker, F., & Regel, S. (2009). Assessment of caring and its effects in young people: development of the Multidimensional Assessment of Caring Activities Checklist (MACA-YC18) and the Positive and Negative Outcomes of Caring Questionnaire (PANOC-YC20) for young carers. *Child Care Health Development, 35*(4), 510-520. doi:10.1111/j.1365-2214.2009.00959.x

Joseph, S., Kendall, C., Toher, D., Sempik, J., Holland, J., & Becker, S. (2019). Young carers in England: Findings from the 2018 BBC survey on the prevalence and nature of caring among young people. *Child Care Health and Development, 45*(4), 606-612. doi:10.1111/cch.12674

Joseph, S., Sempik, J., Leu, A., & Becker, S. (2019). Young carers research, practice and policy: an overview and critical perspective on possible future directions. *Adolescent Research Review*, 1-13. doi:10.1007/s40894-019-00119-9

Jozefiak, T., & Kayed, N. S. (2015). Self- and proxy reports of quality of life among adolescents living in residential youth care compared to adolescents in the general population and mental health services. *Health and Quality of Life Outcomes, 13*(1), 104. doi:10.1186/s12955-015-0280-y

Jozefiak, T., Larsson, B., & Wichstrom, L. (2009). Changes in quality of life among Norwegian school children: a six-month follow-up study. *Health and Quality of Life Outcomes, 7*, 7. doi:10.1186/1477-7525-7-7

Jozefiak, T., Larsson, B., Wichstrom, L., Wallander, J., & Mattejat, F. (2010). Quality of life as reported by children and parents: a comparison between students and child psychiatric outpatients. *Health and Quality of Life Outcomes, 8*, 136. doi:10.1186/1477-7525-8-136

Jozefiak, T., & Wallander, J. L. (2016). Perceived family functioning, adolescent psychopathology and quality of life in the general population: a 6-month follow-up study. *Quality of Life Research, 25*(4), 959-967. doi:10.1007/s11136-015-1138-9

Jurkovic, G. J. (1997). *Lost childhoods: the plight of the parentified child*. New York, NY: Routledge.

Jurkovic, G. J., Kuperminc, G., Perilla, J., Murphy, A., Ibañez, G., & Casey, S. (2004). Ecological and ethical perspectives on filial responsibility: Implications for primary prevention with immigrant Latino adolescents. *Journal of Primary Prevention, 25*(1), 81-104.

Järkestig-Berggren, U., Bergman, A. S., Eriksson, M., & Priebe, G. (2018). Young carers in Sweden-A pilot study of care activities, view of caring, and psychological well-being. *Child & Family Social Work*. doi:10.1111/cfs.12614

Järkestig-Berggren, U., & Hanson, E. (2016). Children as next of kin: A scoping review of support interventions for children who have a parent with a serious physical illness. *Child Care in Practice, 22*(3), 277-295. doi:10.1080.13575279.2015.1102125

Kaiser, S., & Schulze, G. C. (2015). Between inclusion and participation: young carers who are absent from school. *Journal of Cognitive Education and Psychology, 14*(3), 314-328. doi:10.1891/1945-8959.14.3.314

Kallander, E. K., Brodahl, L., & Kibsgård, H. (2012). *Oversikt over Helse- og omsorgsdepartementets satsing på barn som pårørende 2007-2010 [The Norwegian Directorate of Health]*. Oslo: Helsedirektoratet.

Kallander, E. K., & Vallesverd, V. U. (2015). Unge omsorgsgivere – Barn og unge som har betydelige omsorgsoppgaver In B. S. M. Haugland, K. E. Bugge, M. Trondsen, & S. Gjesdahl (Eds.), *Familier i motbakke. På vei mot bedre støtte til barn som pårørende.* . Oslo: Fagbokforlaget.

Kars, M. C., van Thiel, G. J., van der Graaf, R., Moors, M., de Graeff, A., & van Delden, J. J. (2016). A systematic review of reasons for gatekeeping in palliative care research. *Palliative Medicine, 30*(6), 533-548. doi:10.1177/0269216315616759

Kaura, N., & Sharma, R. (2015). Loneliness and locus of control among adolescents belonging to nuclear and joint families. *The International Journal of Indian Psychology, 3*(1), 58-70.

Kavanaugh, M. S. (2014). Children and adolescents providing care to a parent with Huntington's disease: disease symptoms, caregiving tasks and young carer well-being. *Child & Youth Care Forum, 43*(6), 675-690. doi:10.1007/s10566-014-9258-x

Kavanaugh, M. S., Howard, M., & Banker-Horner, L. (2018). Feasibility of a multidisciplinary caregiving training protocol for young caregivers in families with ALS. *Social Work in Health Care, 57*(1), 1-12. doi:10.1080/00981389.2017.1378284

Kavanaugh, M. S., Noh, H., & Studer, L. (2015). "It'd be nice if someone asked me how I was doing. Like, 'cause I will have an answer": exploring support needs of young carers of a parent with Huntington's disease. *Vulnerable Children and Youth Studies, 10*(1), 12-25. doi:10.1080/17450128.2014.980370

Kavanaugh, M. S., Stamatopoulos, V., Cohen, D., & Zhang, L. (2015). Unacknowledged caregivers: a scoping review of research on caregiving youth in the United States. *Adolescent Research Review, 1*(1), 29-49. doi:10.1007/s40894-015-0015-7

Kelley, M. L., French, A., Bountress, K., Keefe, H. A., Schroeder, V., Steer, K., . . . Gumienny, L. (2007). Parentification and family responsibility in the family of origin of adult children of alcoholics. *Addictive Behaviors, 32*(4), 675-685. doi:10.1016/j.addbeh.2006.06.010

Kelly, G., Devine, P., & McKnight, M. (2017). Lost in translation? The challenges of measuring informal care among children and young people. *International Journal of Care and Caring, 1*(3), 388-406. doi:10.1332/239788217x15084960724368

Knutsson-Medin, L., Edlund, B., & Ramklint, M. (2007). Experiences in a group of grown-up children of mentally ill parents. *Journal of Psychiatric and Mental Health Nursing, 14*(8), 744-752. doi:10.1111/j.1365-2850.2007.01181.x

Kosher, H., & Ben-Arieh, A. (2017). What children think about their rights and their well-being: a cross-national comparison. *American Journal of Orthopsychiatry, 87*(3), 256-273. doi:10.1037/ort0000222

Krattenmacher, T., Kuhne, F., Fuhrer, D., Beierlein, V., Brahler, E., Resch, F., . . . Moller, B. (2013). Coping skills and mental health status in adolescents when a parent has cancer: a multicenter and multi-perspective study. *Journal of Psychosomatic Research, 74*(3), 252-259. doi:10.1016/j.jpsychores.2012.10.003

Krattenmacher, T., Kuhne, F., Halverscheid, S., Wiegand-Grefe, S., Bergelt, C., Romer, G., & Moller, B. (2014). A comparison of the emotional and behavioral problems of children of patients with cancer or a mental disorder and their association with parental quality of life. *Journal of Psychosomatic Research, 76*(3), 213-220. doi:10.1016/j.jpsychores.2013.11.020

Krebber, A. M., Buffart, L. M., Kleijn, G., Riepma, I. C., de Bree, R., Leemans, C. R., . . . Verdonck-de Leeuw, I. M. (2014). Prevalence of depression in cancer patients: a meta-analysis of diagnostic interviews and self-report instruments. *Psycho-Oncology, 23*(2), 121-130. doi:10.1002/pon.3409

Kuhne, F., Krattenmacher, T., Bergelt, C., Beierlein, V., Herzog, W., Klitzing, K. V., . . . Moller, B. (2013). "There is still so much ahead of us"-family functioning in families of palliative cancer patients. *Families, Systems, & Health, 31*(2), 181-193. doi:10.1037/a0032274

Kuhne, F., Krattenmacher, T., Bergelt, C., Ernst, J. C., Flechtner, H. H., Fuhrer, D., . . . Moller, B. (2012). Parental palliative cancer: psychosocial adjustment and health-related quality of life in adolescents participating in a German family counselling service. *BMC Palliative Care, 11*(1), 21. doi:10.1186/1472-684x-11-21

Kvarme, L. G., Haraldstad, K., Helseth, S., Sorum, R., & Natvig, G. K. (2009). Associations between general self-efficacy and health-related quality of life among 12-13-year-old school children: a cross-sectional survey. *Health and Quality of Life Outcomes, 7*, 85. doi:10.1186/1477-7525-7-85

Kvello, Ø. (2010). *Barn i risiko. Skadelige omsorgssituasjoner*. Oslo: Gyldendal Akademiske.

Lackey, N. R., & Gates, M. F. (2001). Adults' recollections of their experiences as young caregivers of family members with chronic physical illnesses. *Journal of Advanced Nursing, 34*(3), 320-328. doi:10.1046/j.1365-2648.2001.01761.x

Lauritzen, C., Reedtz, C., Van Doesum, K. T., & Martinussen, M. (2014). Implementing new routines in adult mental health care to identify and support children of mentally ill parents. *BMC Health Services Research, 14*(1), 58. doi:10.1186/1472-6963-14-58

Lauritzen, C., Vis, S. A., Havnen, K. J. S., & Fossum, S. (2017). *Barnevernets undersøkelsesarbeid - Evaluering av Kvellomalen. Delrapport 2*. Tromsø: RKBU Nord.

Leu, A., & Becker, S. (2016). A cross-national and comparative classification of in-country awareness and policy responses to 'young carers'. *Journal of Youth Studies, 20*(6), 750-762. doi:10.1080/13676261.2016.1260698

Leu, A., Frech, M., & Jung, C. (2018). Young carers and young adult carers in Switzerland: Caring roles, ways into care and the meaning of communication. *Health and Social Care in the Community, 26*(6), 925-934. doi:10.1111/hsc.12622

Leu, A., Frech, M., Wepf, H., Sempik, J., Joseph, S., Helbling, L., . . . Jung, C. (2019). Counting young carers in Switzerland–a study of prevalence. *Children & Society, 33*(1), 53-67. doi:10.1111/chso.12296

Lloyd, K. (2012). Happiness and well-being of young carers: Extent, nature and correlates of caring among 10 and 11 year old school children. *J Happiness Stud, 14*(1), 67-80. doi:10.1007/s10902-011-9316-0

Loechner, J., Starman, K., Galuschka, K., Tamm, J., Schulte-Korne, G., Rubel, J., & Platt, B. (2018). Preventing depression in the offspring of parents with depression: A systematic review and meta-analysis of randomized controlled trials. *Clinical Psychology Review, 60*, 1-14. doi:10.1016/j.cpr.2017.11.009

Macfie, J., Brumariu, L. E., & Lyons-Ruth, K. (2015). Parent–child role-confusion: A critical review of an emerging concept. *Developmental Review, 36*, 34-57. doi:10.1016/j.dr.2015.01.002

Manger, T., & Eikeland, O. J. (2000). On the relationship between locus of control, level of ability and gender. *Scandinavian Journal of Psychology, 41*(3), 225-229. doi:10.1111/1467-9450.00191

Martinsen, E. H., Weimand, B. M., Pedersen, R., & Norvoll, R. (2017). The silent world of young next of kin in mental healthcare. *Nursing Ethics*. doi:10.1177/0969733017694498

Matza, L. S., Swensen, A. R., Flood, E. M., Secnik, K., & Leidy, N. K. (2004). Assessment of health-related quality of life in children: a review of conceptual, methodological, and regulatory issues. *Value in Health, 7*(1), 79-92. doi:10.1111/j.1524-4733.2004.71273.x

Mauseth, T., & Hjalmhult, E. (2016). Adolescents' experiences on coping with parental multiple sclerosis: a grounded theory study. *Journal of Clinical Nursing, 25*(5-6), 856-865. doi:10.1111/jocn.13131

McDougall, E., O'Connor, M., & Howell, J. (2018). "Something that happens at home and stays at home": An exploration of the lived experience of young carers in Western Australia. *Health and Social Care in the Community, 26*(4), 572-580. doi:10.1111/hsc.12547

Meade, T., & Dowswell, E. (2016). Adolescents' health-related quality of life (HRQoL) changes over time: a three year longitudinal study. *Health and Quality of Life Outcomes, 14*(1), 14. doi:10.1186/s12955-016-0415-9

Mechling, B. M. (2015). A cross-sectional survey of the effect on emerging adults living with a depressed parent. *Journal of Psychiatric and Mental Health Nursing, 22*(8), 570-578. doi:10.1111/jpm.12244

Meier, M., & Bureau, J. F. (2018). The Development, Psychometric Analyses and Correlates of a Self-Report Measure on Disorganization and Role Reversal. *Journal of child and family studies, 27*(6), 1805-1817. doi:10.1007/s10826-018-1028-1

Merz, E. L., Roesch, S. C., Malcarne, V. L., Penedo, F. J., Llabre, M. M., Weitzman, O. B., . . . Gallo, L. C. (2014). Validation of interpersonal support evaluation list-12 (ISEL-12) scores among English- and Spanish-speaking Hispanics/Latinos from the HCHS/SOL sociocultural ancillary study. *Psychological Assessment, 26*(2), 384-394. doi:10.1037/a0035248

Metzing-Blau, S., & Schnepp, W. (2008). Young carers in Germany: to live on as normal as possible - a grounded theory study. *BMC Nursing, 7*(1), 15. doi:10.1186/1472-6955-7-15

Miller, I. W., Ryan, C. E., Keitner, G. I., Bishop, D. S., & Epstein, N. B. (2000). The McMaster approach to families: theory, assessment, treatment and research. *Journal of Family Therapy, 22*(2), 168-189. doi:Doi 10.1111/1467-6427.00145

Minuchin, S. (1967). *Families of the slums: An exploration of their structure and treatment*. New York: Basic Books.

Moberg, J. Y., Larsen, D., & Brodsgaard, A. (2017). Striving for balance between caring and restraint: young adults' experiences with parental multiple sclerosis. *Journal of Clinical Nursing, 26*(9-10), 1363-1374. doi:10.1111/jocn.13587

Moore, T. (2005). Young carers and education: Identifying the barriers to satisfactory education for young carers. *Youth Studies Australia, 24*(4), 50-55.

Moore, T., & McArthur, M. (2007). We're all in it together: supporting young carers and their families in Australia. *Health and Social Care in the Community, 15*(6), 561-568. doi:10.1111/j.1365-2524.2007.00719.x

Moore, T., McArthur, M., & Morrow, R. (2009). Attendance, achievement and participation: Young carers' experiences of school in Australia. *Australian journal of education, 53*(1), 5-18.

Moore, T., McArthur, M., & Noble-Carr, D. (2011). Different but the same? Exploring the experiences of young people caring for a parent with an alcohol or other drug issue. *Journal of Youth Studies, 14*(2), 161-177. doi:10.1080/13676261.2010.522561

Mordoch, E., & Hall, W. A. (2002). Children living with a parent who has a mental illness: A critical analysis of the literature and research implications. *Archives of Psychiatric Nursing, 16*(5), 208-216. doi:10.1053/apnu.2002.36231

Morley, D., Selai, C., Schrag, A., Jahanshahi, M., & Thompson, A. (2011). Adolescent and adult children of parents with Parkinson's disease: incorporating their needs in clinical guidelines. *Parkinson's Disease, 2011*, 951874. doi:10.4061/2011/951874

Morley, D., Selai, C., Schrag, A., Thompson, A. J., & Jahanshahi, M. (2010). Refinement and validation of the Parental Illness Impact Scale. *Parkinsonism & Related Disorders, 16*(3), 181-185. doi:10.1016/j.parkreldis.2009.11.001

Morris, J. N., Martini, A., & Preen, D. (2016). The well-being of children impacted by a parent with cancer: an integrative review. *Supportive Care in Cancer, 24*(7), 3235-3251. doi:10.1007/s00520-016-3214-2

Munthèn, L. K. (1998-2015). *MBO: Mplus User's Guide. Seventh edition*. Los Angeles, CA: Munthèn & Munthèn.

Nagl-Cupal, M., Daniel, M., Koller, M. M., & Mayer, H. (2014). Prevalence and effects of caregiving on children. *Journal of Advanced Nursing, 70*(10), 2314-2325. doi:10.1111/jan.12388

Nagl-Cupal, M., & Hauprich, J. (2018). Being we and being me: Exploring the needs of Austrian families with caring children. *Health and Social Care in the Community, 26*(4), e532-e540. doi:10.1111/hsc.12567

Najman, J. M., Williams, G. M., Nikles, J., Spence, S., Bor, W., O'Callaghan, M., . . . Andersen, M. J. (2000). Mothers' mental illness and child behavior problems: cause-effect association or observation bias? *Journal of the American Academy of Child and Adolescent Psychiatry, 39*(5), 592-602. doi:10.1097/00004583-200005000-00013

Najman, J. M., Williams, G. M., Nikles, J., Spence, S., Bor, W., O'Callaghan, M., . . . Shuttlewood, G. J. (2001). Bias influencing maternal reports of child behaviour and emotional state. *Social Psychiatry and Psychiatric Epidemiology, 36*(4), 186-194.

Neger, E. N., & Prinz, R. J. (2015). Interventions to address parenting and parental substance abuse: conceptual and methodological considerations. *Clinical Psychology Review, 39*, 71-82. doi:10.1016/j.cpr.2015.04.004

Nes, R. B., Hansen, T., & Barstad, A. (2018). *Livskvalitet. Anbefalinger for et bedre målsesystem [The Norwegian Directorate of Health]*. Oslo: Helsedirektoratet Retrieved from https://helsedirektoratet.no/Lists/Publikasjoner/Attachments/1463/Livskvalitet.%20Anbefalinger%20for%20et%20bedre%20m%C3%A5lesystem%20IS-2727.pdf.

Nicholls, W., Patterson, P., McDonald, F. E., & Hulbert-Williams, N. J. (2017). Unmet needs in young adults with a parent with a chronic condition: a mixed-method investigation and measure development study. *Scandinavian Journal of Caring Sciences, 31*(1), 191-200. doi:10.1111/scs.12320

Nichols, K. R., Fam, D., Cook, C., Pearce, M., Elliot, G., Baago, S., . . . Chow, T. W. (2013). When dementia is in the house: needs assessment survey for young caregivers. *Canadian Journal of Neurological Sciences, 40*(1), 21-28. doi:Doi 10.1017/S0317167100012907

Nicholson, J., & Friesen, B. J. (2014). Developing the evidence base for families living with parental psychiatric disabilities: crossing the bridge while we're building it. *Psychiatric rehabilitation journal, 37*(3), 157-161. doi:10.1037/prj0000092

Nickels, M., Siskowski, C., Lebron, C. N., & Belkowitz, J. (2018). Medication administration by caregiving youth: An inside look at how adolescents manage medications for family members. *Journal of Adolescence, 69*, 33-43. doi:10.1016/j.adolescence.2018.09.001

Nilsen, A. C., & Wærdahl, R. (2015). Gender differences in Norwegian children's work at home *Childhood, 22*(1), 53-66. doi:10.1177/0907568213518082

Nordenfors, M., & Melander, C. (2017). Young carers in Sweden - A short overview.   Retrieved from http://www.anhoriga.se/Global/BSA/Dokument/Rapporter_kunskaps%C3%B6versikter/YoungCarers_Sweden_2017.pdf

Nordenfors, M., Melander, C., & Daneback, K. (2014). Unga omsorgsgivare i Sverige. Rapport 2014:5 Retrieved from http://www.anhoriga.se/Global/BSA/Dokument/Rapporter_kunskaps%C3%B6versikter/Nka_BSA_Rapport_2014-5_webb.pdf

NOU 2009: 8. (2009). *Kompetanseutvikling i barnevernet— Kvalifisering til arbeid i barnevernet gjennom praksisnær og forskningsbasert utdanning [The Norwegian Ministry of Children and Equality]*. Oslo: Barne- og likestillingsdepartementet Retrieved from https://www.regjeringen.no/no/dokumenter/nou-2009-08/id558007/.

NOU 2011: 17. (2011). *Når sant skal sies om pårørendeomsorg — Fra usynlig til verdsatt og inkludert*. Oslo: Helse- og omsorgsdepartementet Retrieved from https://www.regjeringen.no/contentassets/405c4c2d84704979a84027741d237338/no/pdfs/nou201120110017000dddpdfs.pdf.

NOU 2012: 5. (2012). *Bedre beskyttelse av barns utvikling. Ekspertutvalgets utredning om det biologiske prinsipp i barnevernet [The Norwegain Ministery of Child and Equality]*. Oslo: Barne- og likestillingsdepartementet Retrieved from https://www.regjeringen.no/no/dokumenter/nou-2012-5/id671400/.

Nowicki, S., & Strickland, B. R. (1973). A locus of control scale for children. *Journal of Consulting and Clinical Psychology, 40*(1), 148–154 doi:10.1037/h0033978

OECD. (2016). Enhancing child well-being to promote inclusive growth.   Retrieved from http://www.oecd.org/officialdocuments/publicdisplaydocumentpdf/?cote=DELSA/ELSA(2016)7/REV1&doclanguage=en

OECD. (2018). Is the last mile the longest? Economic gains from gender equality in Nordic countries. Retrieved from https://read.oecd-ilibrary.org/social-issues-migration-health/is-the-last-mile-the-longest-economic-gains-from-gender-equality-in-nordic-countries_9789264300040-en#page1

Ogden, T. (2003). The validity of teacher ratings of adolescents' social skills. *Scandinavian Journal of Educational Research, 47*(1), 63-76. doi:10.1080/00313830308605

Olson, D. H. (1986). Circumplex model VII: validation studies and FACES III. *Family Process, 25*(3), 337-351.

Olson, D. H., Portner, J., & Lavee, Y. (1985). *Faces-III: family adaptability and cohesion evaluation scale* St. Paul (Minn.) Social Science, University of Minnesota.

Ordway, M. R. (2011). Depressed mothers as informants on child behavior: methodological issues. *Research in Nursing and Health, 34*(6), 520-532. doi:10.1002/nur.20463

Osborn, T. (2007). The psychosocial impact of parental cancer on children and adolescents: a systematic review. *Psycho-Oncology, 16*(2), 101-126. doi:10.1002/pon.1113

Pakenham, K. I., & Bursnall, S. (2006). Relations between social support, appraisal and coping and both positive and negative outcomes for children of a parent with multiple sclerosis and comparisons with children of healthy parents. *Clinical Rehabilitation, 20*(8), 709-723. doi:10.1191/0269215506cre976oa

Pakenham, K. I., Bursnall, S., Chiu, J., Cannon, T., & Okochi, M. (2006). The psychosocial impact of caregiving on young people who have a parent with an illness or disability: Comparisons between young caregivers and noncaregivers. *Rehabilitation Psychology, 51*(2), 113-126. doi:10.1037/0090-5550.51.2.113

Pakenham, K. I., Chiu, J., Bursnall, S., & Cannon, T. (2007). Relations between social support, appraisal and coping and both positive and negative outcomes in young carers. *Journal of Health Psychology, 12*(1), 89-102. doi:10.1177/1359105307071743

Pakenham, K. I., & Cox, S. (2012a). The nature of caregiving in children of a parent with multiple sclerosis from multiple sources and the associations between caregiving activities and youth adjustment overtime. *Psychology & Health, 27*(3), 324-346. doi:10.1080/08870446.2011.563853

Pakenham, K. I., & Cox, S. (2012b). Test of a model of the effects of parental illness on youth and family functioning. *Health Psychology, 31*(5), 580-590. doi:10.1037/a0026530

Pakenham, K. I., & Cox, S. (2013). Comparisons between youth of a parent with MS and a control group on adjustment, caregiving, attachment and family functioning. *Psychology & Health, 29*(1), 1-15. doi:10.1080/08870446.2013.813944

Pakenham, K. I., & Cox, S. (2014). The effects of parental illness and other ill family members on the adjustment of children. *Annals of Behavioral Medicine, 48*(3), 424-437. doi:10.1007/s12160-014-9622-y

Pakenham, K. I., & Cox, S. (2015). The effects of parental illness and other ill family members on youth caregiving experiences. *Psychology & Health, 30*(7), 857-878. doi:10.1080/08870446.2014.1001390

Pakenham, K. I., & Cox, S. (2018). Effects of benefit finding, social support and saregiving on youth sdjustment in a parental illness context. *Journal of child and family studies, 27*(8), 2491-2506. doi:10.1007/s10826-018-1088-2

Patterson, J. M., & Garwick, A. W. (1994). The impact of chronic illness on families: A family systems perspective. *Annals of Behavioral Medicine, 16*(2), 131-142. doi:10.1093/abm/16.2.131

Patterson, P., McDonald, F. E. J., Butow, P., White, K. J., Costa, D. S. J., Pearce, A., & Bell, M. L. (2013). Psychometric evaluation of the Offspring Cancer Needs Instrument (OCNI): an instrument to assess the psychosocial unmet needs of young people who have a parent with cancer. *Supportive Care in Cancer, 21*(7), 1927-1938. doi:10.1007/s00520-013-1749-z

Pedersen, S., & Revenson, T. A. (2005). Parental illness, family functioning, and adolescent well-being: a family ecology framework to guide research. *Journal of Family Psychology, 19*(3), 404-419. doi:10.1037/0893-3200.19.3.404

Prout, A., & James, A. (2003). *Constructing and reconstructing childhood: Contemporary issues in the sociological study of childhood*. London: UK Falmer Press.

Pölkki, P., Ervast, S., & Huupponen, M. (2005). Coping and resilience of children of a mentally ill parent. *Social Work in Health Care, 39*(1-2), 151-163. doi:10.1300/J010v39n01_10

Quitmann, J., Kriston, L., Romer, G., & Ramsauer, B. (2012). The capacity to see things from the child's point of view--assessing insightfulness in mothers with and without a diagnosis of depression. *Clinical Psychology & Psychotherapy, 19*(6), 508-517. doi:10.1002/cpp.759

Quitmann, J., Rohenkohl, A., Sommer, R., Bullinger, M., & Silva, N. (2016). Explaining parent-child (dis)agreement in generic and short stature-specific health-related quality of life reports: do family and social relationships matter? *Health and Quality of Life Outcomes, 14*(1), 150. doi:10.1186/s12955-016-0553-0

Raknes, S., Pallesen, S., Himle, J. A., Bjaastad, J. F., Wergeland, G. J., Hoffart, A., . . . Haugland, B. S. M. (2017). Quality of life in anxious adolescents. *Child Adolesc Psychiatry Ment Health, 11*(1), 33. doi:10.1186/s13034-017-0173-4

Ravens-Sieberer, U., Auquier, P., Erhart, M., Gosch, A., Rajmil, L., Bruil, J., . . . the European KIDSCREEN Group. (2007). The KIDSCREEN-27 quality of life measure for children and adolescents: psychometric results from a cross-cultural survey in 13 European countries. *Quality of Life Research, 16*(8), 1347-1356. doi:10.1007/s11136-007-9240-2

Ravens-Sieberer, U., Devine, J., Bevans, K., Riley, A. W., Moon, J. H., Salsman, J. M., & Forrest, C. B. (2014). Subjective well-being measures for children were developed within the PROMIS project: presentation of first results. *Journal of Clinical Epidemiology, 67*(2), 207-218. doi:10.1016/j.jclinepi.2013.08.018

Ravens-Sieberer, U., Erhart, M., Wille, N., Wetzel, R., Nickel, J., & Bullinger, M. (2006). Generic health-related quality-of-life assessment in children and adolescents: methodological considerations. *Pharmacoeconomics, 24*(12), 1199-1220. doi:10.2165/00019053-200624120-00005

Ravens-Sieberer, U., Gosch, A., Abel, T., Auquier, P., Bellach, B. M., Bruil, J., . . . the European KIDSCREEN Group. (2001). Quality of life in children and adolescents: a European public health perspective. *Sozial- und Praventivmedizin, 46*(5), 294-302.

Ravens-Sieberer, U., Herdman, M., Devine, J., Otto, C., Bullinger, M., Rose, M., & Klasen, F. (2014). The European KIDSCREEN approach to measure quality of life and well-being in children:

development, current application, and future advances. *Quality of Life Research, 23*(3), 791-803. doi:10.1007/s11136-013-0428-3

Ravens-Sieberer, U., Horka, H., Illyes, A., Rajmil, L., Ottova-Jordan, V., & Erhart, M. (2013). Children's quality of life in Europe: national wealth and familial socioeconomic position explain variations in mental health and wellbeing—a multilevel analysis in 27 EU countries. *ISRN Public Health, 2013*, 1-9. doi:10.1155/2013/419530

Razaz, N., Nourian, R., Marrie, R. A., Boyce, W. T., & Tremlett, H. (2014). Children and adolescents adjustment to parental multiple sclerosis: a systematic review. *BMC Neurology, 14*(1), 107. doi:10.1186/1471-2377-14-107

Reedtz, C., Lauritzen, C., & van Doesum, K. T. (2012). Evaluating workforce developments to support children of mentally ill parents: implementing new interventions in the adult mental healthcare in Northern Norway. *BMJ Open, 2*(3). doi:10.1136/bmjopen-2011-000709

Ringoot, A. P., Tiemeier, H., Jaddoe, V. W., So, P., Hofman, A., Verhulst, F. C., & Jansen, P. W. (2015). Parental depression and child well-being: young children's self-reports helped addressing biases in parent reports. *Journal of Clinical Epidemiology, 68*(8), 928-938. doi:10.1016/j.jclinepi.2015.03.009

Roazzi, A., Attili, G., Di Pentima, L., & Toni, A. (2016). Locus of control in maltreated children: the impact of attachment and cumulative trauma. *Psicologia-Reflexao E Critica, 29*(1), 8. doi:10.1186/s41155-016-0025-9

Rolland, J. S. (1999). Parental illness and disability: a family systems framework. *Journal of Family Therapy, 21*(3), 242-266. doi:10.1111/1467-6427.00118

Romer, G., Saha, R., Haagen, M., Pott, M., Baldus, C., & Bergelt, C. (2007). Lessons learned in the implementation of an innovative consultation and liaison service for children of cancer patients in various hospital settings. *Psycho-Oncology, 16*(2), 138-148. doi:10.1002/pon.1105

Rose, H. D., & Cohen, K. (2010). The experiences of young carers: a meta-synthesis of qualitative findings. *Journal of Youth Studies, 13*(4), 473-487. doi:10.1080/13676261003801739

Rossow, I., Felix, L., Keating, P., & McCambridge, J. (2016). Parental drinking and adverse outcomes in children: A scoping review of cohort studies. *Drug Alcohol Rev, 35*(4), 397-405. doi:10.1111/dar.12319

Rotter, J. B. (1966). Generalized expectancies for internal versus external control of reinforcement. *Psychological Monographs, 80*(1), 1-28. doi:10.1037/h0092976

Ruud, T., Birkeland, B., Faugli, A., Hagen, K. A., Hellman, A., Hilsen, M., . . . Weimand, B. M. (2015). *Barn som pårørende -Resultater fra en multisenterstudie (Children as next of kin -results from a multi-centre project)* (IS-05022). Lørenskog: Akershus: Akershus Universitetssykehus.

Sattoe, J. N., van Staa, A., Moll, H. A., & On Your Own Feet Research Group. (2012). The proxy problem anatomized: child-parent disagreement in health related quality of life reports of chronically ill adolescents. *Health and Quality of Life Outcomes, 10*, 10. doi:10.1186/1477-7525-10-10

Schlarmann, J. G., Metzing-Blau, S., & Schnepp, W. (2008). The use of health-related quality of life (HRQOL) in children and adolescents as an outcome criterion to evaluate family oriented support for young carers in Germany: an integrative review of the literature. *BMC Public Health, 8*, 414. doi:10.1186/1471-2458-8-414

Schleider, J. L., Ginsburg, G. S., Keeton, C. P., Weisz, J. R., Birmaher, B., Kendall, P. C., . . . Walkup, J. T. (2015). Parental psychopathology and treatment outcome for anxious youth: roles of family functioning and caregiver strain. *Journal of Consulting and Clinical Psychology, 83*(1), 213-224. doi:10.1037/a0037935

Schmitt, F., Piha, J., Helenius, H., Baldus, C., Kienbacher, C., Steck, B., . . . Romer, G. (2008). Multinational study of cancer patients and their children: factors associated with family functioning. *Journal of Clinical Oncology, 26*(36), 5877-5883. doi:10.1200/JCO.2007.12.8132

Scottish Government. (2010). *Getting it Right for Young Carers. The Young Carers Strategy for Scotland 2010-2015.* Edinburgh: Scottish Government Retrieved from https://www2.gov.scot/Resource/Doc/319441/0102105.pdf.

Scottish Government. (2017). *Young carers: Review of research and data*. Edinburgh: Scottis Goverment Retrieved from https://www.gov.scot/binaries/content/documents/govscot/publications/research-publication/2017/03/young-carers-review-research-data/documents/00514848-pdf/00514848-pdf/govscot%3Adocument.

Seaberg, J. R. (1990). Child well-being: A feasible concept? *Social Work, 35*(3), 267-272.

Seid, M., Varni, J. W., & Jacobs, J. R. (2000). Pediatric health-related quality-of-life measurement technology: Intersections between science, managed care, and clinical care. *Journal of Clinical Psychology in Medical Settings, 7*(1), 17-27. doi:Doi 10.1023/A:1009541218764

Selbekk, A. S., Adams, P. J., & Sagvaag, H. (2018). “A Problem Like This Is Not Owned by an Individual”. *Contemporary Drug Problems, 45*(2), 146-162. doi:10.1177/0091450918773097

Seligson, J. L., Huebner, E. S., & Valois, R. F. (2003). Preliminary validation of the Brief Multidimensional Students' Life Satisfaction Scale (BMSLSS). *Social Indicators Research, 61*(2), 121-145. doi:Doi 10.1023/A:1021326822957

Sharkey, K., Savulescu, J., Aranda, S., & Schofield, P. (2010). Clinician gate-keeping in clinical research is not ethically defensible: an analysis. *Journal of Medical Ethics, 36*(6), 363-366. doi:10.1136/jme.2009.031716

Sharpe, H., Patalay, P., Fink, E., Vostanis, P., Deighton, J., & Wolpert, M. (2016). Exploring the relationship between quality of life and mental health problems in children: implications for measurement and practice. *European Child and Adolescent Psychiatry, 25*(6), 659-667. doi:10.1007/s00787-015-0774-5

Shifren, K., & Chong, A. (2012). Health-Related Behaviors: A Study Among Former Young Caregivers. *Journal of Adult Development, 19*(2), 111-121. doi:10.1007/s10804-011-9140-0

Shifren, K., Hillman, A., & Rowe, A. (2014). Early caregiver experiences, optimism, and mental health: Former young caregivers and emerging adult caregivers. *International Journal of Psychology Research, 9*(4), 361.

Sieh, D. S., Dikkers, A. L., Visser-Meily, J. M., & Meijer, A. M. (2012). Stress in adolescents with a chronically ill parent: inspiration from Rolland's family systems-illness model. *Journal of Developmental and Physical Disabilities, 24*(6), 591-606. doi:10.1007/s10882-012-9291-3

Sieh, D. S., Meijer, A. M., Oort, F. J., Visser-Meily, J. M., & Van der Leij, D. A. (2010). Problem behavior in children of chronically ill parents: a meta-analysis. *Clinical Child and Family Psychology Review, 13*(4), 384-397. doi:10.1007/s10567-010-0074-z

Sieh, D. S., Meijer, A. M., & Visser-Meily, J. M. (2010). Risk factors for stress in children after parental stroke. *Rehabilitation Psychology, 55*(4), 391-397. doi:10.1037/a0020918

Sieh, D. S., Visser-Meily, J. M., & Meijer, A. M. (2013a). Differential Outcomes of Adolescents with Chronically Ill and Healthy Parents. *Journal of child and family studies, 22*(2), 209-218. doi:10.1007/s10826-012-9570-8

Sieh, D. S., Visser-Meily, J. M., & Meijer, A. M. (2013b). The relationship between parental depressive symptoms, family type, and adolescent functioning. *PloS One, 8*(11), e80699. doi:10.1371/journal.pone.0080699

Sieh, D. S., Visser-Meily, J. M., Oort, F. J., & Meijer, A. M. (2012). Risk factors for problem behavior in adolescents of parents with a chronic medical condition. *European Child and Adolescent Psychiatry, 21*(8), 459-471. doi:10.1007/s00787-012-0279-4

Skinner, H. A., Steinhauer, P. D., & Santa-Barbara, J. (2009). The family assessment measure. *Canadian Journal of Community Mental Health, 2*(2), 91-103. doi:10.7870/cjcmh-1983-0018

Skogøy, B. E., Maybery, D., Ruud, T., Sorgaard, K., Peck, G. C., Kufas, E., . . . Ogden, T. (2018). Differences in implementation of family focused practice in hospitals: a cross-sectional study. *Int J Ment Health Syst, 12*(1), 77. doi:10.1186/s13033-018-0256-5

Skogøy, B. E., Sorgaard, K., Maybery, D., Ruud, T., Stavnes, K., Kufas, E., . . . Ogden, T. (2018). Hospitals implementing changes in law to protect children of ill parents: a cross-sectional study. *BMC Health Services Research, 18*(1), 609. doi:10.1186/s12913-018-3393-2

Smyth, C., Blaxland, M., & Cass, B. (2010). ‘So that's how I found out I was a young carer and that I actually had been a carer most of my life’. Identifying and supporting hidden young carers. *Journal of Youth Studies, 14*(2), 145-160. doi:10.1080/13676261.2010.506524

Smyth, C., Cass, B., & Hill, T. (2011). Children and young people as active agents in care-giving: Agency and constraint. *Children and Youth Services Review, 33*(4), 509-514. doi:10.1016/j.childyouth.2010.05.009

Solans, M., Pane, S., Estrada, M. D., Serra-Sutton, V., Berra, S., Herdman, M., . . . Rajmil, L. (2008). Health-related quality of life measurement in children and adolescents: a systematic review of generic and disease-specific instruments. *Value in Health, 11*(4), 742-764. doi:10.1111/j.1524-4733.2007.00293.x

Sosial- og helsedirektoratet. (2007). *Psykisk helsearbeid for barn og unge i kommunene [The Norwegian Directorate of Social- and Health].* (Veileder IS-1405). Oslo: Sosial- og helsedirektoratet Retrieved from https://helsedirektoratet.no/retningslinjer/veileder-i-psykisk-helsearbeid-for-barn-og-unge-i-kommunene.

Spinrad, T. L., & Eisenberg, N. (2017). Prosocial behavior and empathy-related responding: Relations to children's well-being *The happy mind: Cognitive contributions to well-being* (pp. 331-347). Dordrecht: Springer.

Sprung, S., & Laing, M. (2017). Young carer awareness, identification and referral. *British Journal of Community Nursing, 22*(8).

Stamatopoulos, V. (2015). One million and counting: the hidden army of young carers in Canada. *Journal of Youth Studies, 18*(6), 809-822. doi:10.1080/13676261.2014.992329

Stamatopoulos, V. (2018). The young carer penalty: Exploring the costs of caregiving among a sample of Canadian youth. *Child & Youth Services, 39*(2-3), 180-205. doi:10.1080/0145935x.2018.1491303

Statham, J., & Chase, E. (2010). Childhood wellbeing: A brief overview. Retrieved from http://www.cwrc.ac.uk/documents/CWRC_Briefing_paper.pdf

Statistisk Sentralbyrå. (2012a). Døgnet rundt fra 1971 til 2010. 2012/4 [Statistics Norway]. *Samfunnsspeilet.* Retrieved from https://www.ssb.no/a/samfunnsspeilet/utg/201204/ssp.pdf

Statistisk Sentralbyrå. (2012b). Tidsbruksundersøkelsen 2010. Dokumentasjon av datainnsamling, analyse av datakvalitet og beregning av frafallsvekter [Statistics Norway]. Retrieved from https://www.ssb.no/kultur-og-fritid/artikler-og-publikasjoner/tidsbruksundersokelsen-2010

Statistisk Sentralbyrå. (2013). Barn og unge i befolkningen. Demografisk bilde av norske barn [Statistics Norway]. Retrieved from https://www.ssb.no/a/barnogunge/2013/bef/

Statistisk Sentralbyrå. (2016). Ulønnet omsorgsarbeid, levekårsundersøkelsen [Statistics Norway] Retrieved from https://www.ssb.no/helse/statistikker/omsarb

Staton-Tindall, M., Sprang, G., Clark, J., Walker, R., & Craig, C. D. (2013). Caregiver substance use and child outcomes: A systematic review. *Journal of Social Work Practice in the Addictions, 13*(1), 6-31. doi:10.1080/1533256x.2013.752272

Steck, B., Amsler, F., Grether, A., Dillier, A. S., Baldus, C., Haagen, M., . . . Romer, G. (2007). Mental health problems in children of somatically ill parents, e.g. multiple sclerosis. *European Child and Adolescent Psychiatry, 16*(3), 199-207. doi:10.1007/s00787-006-0589-5

Stein, J. A., Rotheram-Borus, M. J., & Lester, P. (2007). Impact of parentification on long-term outcomes among children of parents with HIV/AIDS. *Family Process, 46*(3), 317-333.

Steinsbekk, S., Jozefiak, T., Odegard, R., & Wichstrom, L. (2009). Impaired parent-reported quality of life in treatment-seeking children with obesity is mediated by high levels of psychopathology. *Quality of Life Research, 18*(9), 1159-1167. doi:10.1007/s11136-009-9535-6

Stenberg, U., Ruland, C. M., & Miaskowski, C. (2010). Review of the literature on the effects of caring for a patient with cancer. *Psycho-Oncology, 19*(10), 1013-1025. doi:10.1002/pon.1670

Strand, B. H., Dalgard, O. S., Tambs, K., & Rognerud, M. (2003). Measuring the mental health status of the Norwegian population: a comparison of the instruments SCL-25, SCL-10, SCL-5 and MHI-5 (SF-36). *Nordic Journal of Psychiatry, 57*(2), 113-118. doi:10.1080/08039480310000932

Svanberg, E., Stott, J., & Spector, A. (2010). 'Just helping': Children living with a parent with young onset dementia. *Aging & Mental Health, 14*(6), 740-751. doi:10.1080/13607861003713174

Sweeney, S., & MacBeth, A. (2016). The effects of paternal depression on child and adolescent outcomes: A systematic review. *Journal of Affective Disorders, 205*, 44-59. doi:10.1016/j.jad.2016.05.073

Syse, A., Aas, G. B., & Loge, J. H. (2012). Children and young adults with parents with cancer: a population-based study. *Clinical Epidemiology, 4*, 41-52. doi:10.2147/CLEP.S28984

Sørlie, M., Hagen, K., & Ogden, T. (2008). Social competence and antisocial behavior: Continuity and distinctiveness across early adolescence. *Journal of research on adolescence, 18*(1), 121–144. doi:10.1111/j.1532-7795.2008.00553

Thastum, M., Watson, M., Kienbacher, C., Piha, J., Steck, B., Zachariae, R., . . . Romer, G. (2009). Prevalence and predictors of emotional and behavioural functioning of children where a parent has cancer: a multinational study. *Cancer, 115*(17), 4030-4039. doi:10.1002/cncr.24449

The KIDSCREEN Group Europe. (2006). *The KIDSCREEN questionnaires - Quality of life questionnaires for children and adolescents. Handbook*. Lengerich, Germany: Pabst Science Publishers.

Tompkins, T. L. (2006). Parentification and maternal HIV infection: beneficial role or pathological burden? *Journal of child and family studies, 16*(1), 108-118. doi:10.1007/s10826-006-9072-7

Torvik, F. A., & Rognmo, K. (2011). Barn av foreldre med psykisk lidelse og alkoholmisbruk; omfang og konsekvenser [Norwegian Institutet of Public Health]. Retrieved from https://www.fhi.no/globalassets/dokumenterfiler/rapporter/2011/rapport-20114-pdf.pdf

Trondsen, M. V. (2012). Living with a mentally ill parent: exploring adolescents' experiences and perspectives. *Qualitative Health Research, 22*(2), 174-188. doi:10.1177/1049732311420736

Trondsen, M. V., & Tjora, A. (2014). Communal normalization in an online self-help group for adolescents with a mentally ill parent. *Qualitative Health Research, 24*(10), 1407-1417. doi:10.1177/1049732314547708

Tsai, K. M., Gonzales, N. A., & Fuligni, A. J. (2016). Mexican A merican Adolescents' Emotional Support to the Family in Response to Parental Stress. *Journal of research on adolescence, 26*(4), 658-672.

Tully, E. C., Donohue, M. R., & Garcia, S. E. (2015). Children's empathy responses and their understanding of mother's emotions. *Cognition & Emotion, 29*(1), 118-129. doi:10.1080/02699931.2014.898614

Turner-Bowker, D. M., Bayliss, M. S., Ware, J. E., & Kosinski, M. (2003). Usefulness of the SF-8 Health Survey for comparing the impact of migraine and other conditions. *Quality of Life Research, 12*(8), 1003-1012.

Tønnessen, S., Kassah, B. L. L., & Tingvoll, W. A. (2016). Samhandling med spesialisthelsetjenesten – sett fra hjemmesykepleiens perspektiv. . *Sykepleien Forskning, 11*(1), 14-23. doi:10.4220/Sykepleienf.2016.56496

Vaage, O. F. (2012). Tidene skifter. Tidsbruk 1971-2010 [Statistics Norway]. Retrieved from https://www.ssb.no/kultur-og-fritid/artikler-og-publikasjoner/tidene-skifter

van der Meiden, J., Noordegraaf, M., & van Ewijk, H. (2018). Applying the paradigm of relational ethics into contextual therapy. Analyzing the practice of Ivan Boszormenyi-Nagy. *Journal of Marital and Family Therapy, 44*(3), 499-511. doi:10.1111/jmft.12262

van der Mijl, R. C., & Vingerhoets, A. J. (2017). The positive effects of parentification: an exploratory study among students. *Psihologijske teme, 26*(2), 417-430.

Van Loon, L. M., Van de Ven, M. O., Van Doesum, K. T., Hosman, C. M., & Witteman, C. L. (2017). Parentification, stress, and problem behavior of adolescents who have a parent with mental health problems. *Family Process, 56*(1), 141-153. doi:10.1111/famp.12165

Van Parys, H., & Rober, P. (2013). Trying to comfort the parent: a qualitative study of children dealing with parental depression. *Journal of Marital and Family Therapy, 39*(3), 330-345. doi:10.1111/j.1752-0606.2012.00304.x

Van Roy, B., Groholt, B., Heyerdahl, S., & Clench-Aas, J. (2010). Understanding discrepancies in parent-child reporting of emotional and behavioural problems: Effects of relational and socio-demographic factors. *BMC Psychiatry, 10*, 56. doi:10.1186/1471-244X-10-56

van Santvoort, F., Hosman, C. M., Janssens, J. M., van Doesum, K. T., Reupert, A., & van Loon, L. M. (2015). The Impact of Various Parental Mental Disorders on Children's Diagnoses: A Systematic Review. *Clinical Child and Family Psychology Review, 18*(4), 281-299. doi:10.1007/s10567-015-0191-9

Vandvik, I. H., & Eckblad, G. F. (1993). FACES III and the Kvebaek Family Sculpture Technique as measures of cohesion and closeness. *Family Process, 32*(2), 221-233. doi:10.1111/j.1545-5300.1993.00221.x

Varni, J. W., Burwinkle, T. M., & Seid, M. (2006). The PedsQL 4.0 as a school population health measure: feasibility, reliability, and validity. *Quality of Life Research, 15*(2), 203-215. doi:10.1007/s11136-005-1388-z

Vella, S. A., Magee, C. A., & Cliff, D. P. (2015). Trajectories and predictors of health-related quality of life during childhood. *Journal of Pediatrics, 167*(2), 422-427. doi:10.1016/j.jpeds.2015.04.079

Visser, A., Huizinga, G. A., van der Graaf, W. T., Hoekstra, H. J., & Hoekstra-Weebers, J. E. (2004). The impact of parental cancer on children and the family: a review of the literature. *Cancer Treatment Reviews, 30*(8), 683-694. doi:10.1016/j.ctrv.2004.06.001

Von Bertalanffy, L. (Ed.) (1968). *General systems theory: Foundations developments, applications. (Rev. ed.)*. New York: Braziller.

von Rueden, U., Gosch, A., Rajmil, L., Bisegger, C., & Ravens-Sieberer, U. (2006). Socioeconomic determinants of health related quality of life in childhood and adolescence: results from a European study. *Journal of Epidemiology and Community Health, 60*(2), 130-135. doi:10.1136/jech.2005.039792

Vulliez-Coady, L., Obsuth, I., Torreiro-Casal, M., Ellertsdottir, L., & Lyons-Ruth, K. (2013). Maternal role confusion: Relations to maternal attachment and mother-child interaction from infancy to adolescence. *Infant Ment Health J, 34*(2), 117-131. doi:10.1002/imhj.21379

Vulliez-Coady, L., Solheim, E., Nahum, J. P., & Lyons-Ruth, K. (2016). Role-confusion in parent-child relationships: Assessing mother's representations and its implications for counselling and psychotherapy practice. *The European Journal of Counselling Psychology, 4*(2), 205-227. doi:10.5964/ejcop.v4i2.62

Walczak, A., McDonald, F., Patterson, P., Dobinson, K., & Allison, K. (2018). How does parental cancer affect adolescent and young adult offspring? A systematic review. *International Journal of Nursing Studies, 77*, 54-80. doi:10.1016/j.ijnurstu.2017.08.017

Wallander, J. L., & Koot, H. M. (2016). Quality of life in children: A critical examination of concepts, approaches, issues, and future directions. *Clinical Psychology Review, 45*, 131-143. doi:10.1016/j.cpr.2015.11.007

Wallander, J. L., Schmitt, M., & Koot, H. M. (2001). Quality of life measurement in children and adolescents: issues, instruments, and applications. *Journal of Clinical Psychology, 57*(4), 571-585.

Wangensteen, T., Bramness, J. G., & Halsa, A. (2018). Growing up with parental substance use disorder: The struggle with complex emotions, regulation of contact, and lack of professional support. *Child & Family Social Work*. doi:10.1111/cfs.12603

Ware, J. E., Kosinski, M., Dewey, J. E., & Gandek, B. (2001). *How to score and interpret single-item health status measures: a manual for users of the SF-8 health survey*. Lincoln, RI: QualityMetric Inc.

Warren, J. (2006). Young carers: Conventional or exaggerated levels of involvement in domestic and caring tasks? *Children & Society, 21*(2), 136–146. doi:10.1111/j.1099-0860.2006.00038.x

Weber, S., Jud, A., Landolt, M. A., & Goldbeck, L. (2017). Predictors of health-related quality of life in maltreated children and adolescents. *Quality of Life Research, 26*(10), 2717-2727. doi:10.1007/s11136-017-1615-4

Weinstein, N., & Ryan, R. M. (2010). When helping helps: autonomous motivation for prosocial behavior and its influence on well-being for the helper and recipient. *Journal of Personality and Social Psychology, 98*(2), 222-244. doi:10.1037/a0016984

Weissman, M. M., Wickramaratne, P., Pilowsky, D. J., Poh, E., Batten, L. A., Hernandez, M., . . . Stewart, J. W. (2015). Treatment of maternal depression in a medication clinical trial and its effect on children. *American Journal of Psychiatry, 172*(5), 450-459. doi:10.1176/appi.ajp.2014.13121679

Werner, A., & Malterud, K. (2016). Children of parents with alcohol problems performing normality: A qualitative interview study about unmet needs for professional support. *International Journal of Qualitative Studies on Health and Well-Being, 11*(1), 30673. doi:10.3402/qhw.v11.30673

West, M. L., & Keller, A. E. R. (1991). Parentification of the child: A case study of Bowlby's compulsive care-giving attachment pattern. *American Journal of Psychotherapy, 45*(3), 425-431.

Wiig, E. M., Halsa, A., Bramness, J., Myra, S. M., & Haugland, B. S. M. (2018). Rescue the child or treat the adult? Understandings among professionals in dual treatment of substance-use disorders and parenting. *Nordic Studies on Alcohol and Drugs, 35*(3), 179-195. doi:10.1177/1455072518773615

Williams, K., & Francis, S. E. (2010). Parentification and psychological adjustment: Locus of control as a moderating variable. *Contemporary Family Therapy, 32*(3), 231-237. doi:10.1007/s10591-010-9123-5

Winton, C. A. (2003). *Children as caregivers: Parental and parentified children*. Boston: Allyn & Bacon.

Yamamoto, R., & Keogh, B. (2018). Children's experiences of living with a parent with mental illness: A systematic review of qualitative studies using thematic analysis. *Journal of Psychiatric and Mental Health Nursing, 25*(2), 131-141. doi:10.1111/jpm.12415

Young Carers Research Group. YC-QST-20 (Mental Health) Guidance. Retrieved from www.ycrg.org.uk/.../YCQST20EXMODELMentalHealth.pdf

Young Carers Research Group. YC-QST-20 (Mental health) Young Carers: Questionnaire and Screening Tool (Identifying and Recognising Young Carers). Retrieved from http://www.ycrg.org.uk/youngCarersDownload/YCRG%20questionnaire.pdf

Ytterhus, B. (2012). Hva er et "pårørende barn"? Barn mellom risiko, nytte og en åpen fremtid. In B. Y. BSM Haugland, & K. Dyregrov (Ed.), *Barn som pårørende*. Oslo: Abstrakt forlag AS.

Zullig, K. J., Valois, R. F., & Drane, J. W. (2005). Adolescent distinctions between quality of life and self-rated health in quality of life research. *Health and Quality of Life Outcomes, 3*(1), 64. doi:10.1186/1477-7525-3-64

Zullig, K. J., Valois, R. F., Huebner, E. S., & Drane, J. W. (2005). Adolescent health-related quality of life and perceived satisfaction with life. *Quality of Life Research, 14*(6), 1573-1584. doi:10.1007/s11136-004-7707-y

Östman, M. (2008). Interviews with children of persons with a severe mental illness: investigating their everyday situation. *Nordic Journal of Psychiatry, 62*(5), 354-359. doi:10.1080/08039480801960065

Östman, M., & Kjellin, L. (2002). Stigma by association - Psychological factors in relatives of people with mental illness. *British Journal of Psychiatry, 181*(6), 494-498. doi:10.1192/bjp.181.6.494

Errataliste

Navn kandidat: Ellen Katrine Kallander

Avhandlingstittel:

Children affected by parental illness: young carers, well-being and quality of life

Forkortelser for type rettelser:

Cor – korrektur

Celtf – endring av sielayout eller tekstformat

Side	Linje	Originaltekst	Type rettelse	Korrigert tekst
6	32	…emotional illness…	Cor	…mental illness…
22	Andre avsnitt, linje 3	…processoriented..	Cor	…process oriented…
22	Andre avsnitt, linje 5	..processoriented..	Cor	…process oriented…

Appendix I

Documentation of approval

1. Approval of project from South and East Regional Committee for Medical and Health Research Ethics, Norway
2. Approval of project from the Privacy Ombudsman, Akerhus University Hospital, Vestre Viken Hospital Trust, Sørlandet Hospital (HF), Rogaland A-Senter, and Nordland Hospital Trust

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK sør-øst	Elin Evju Sagbakken	22845502	27.12.2016	2012/1176/REK sør-øst A
			Deres dato:	**Deres referanse:**
			21.12.2016	

Vår referanse må oppgis ved alle henvendelser

Torleif Ruud
FOU-avdeling psykisk helsevern

2012/1176 Barn av pasienter med alvorlig sykdom eller rusmiddelmisbruk

Forskningsansvarlig:
Nordlandssykehuset, Vestre Viken HF, Stavanger Universitetssjukehus Helse Stavanger HF, Rogaland A-senter, Regionsenter for barn og unges psykiske helse, BarnsBeste - nasjonalt kompetansenettverk for barn som pårørende , Akershus universitetssykehus, Divisjon for psykisk helsevern.

Prosjektleder: Torleif Ruud

Vi viser til søknad om prosjektendring datert 21.12.2016 for ovennevnte forskningsprosjekt. Søknaden er behandlet av leder for REK sør-øst på fullmakt, med hjemmel i helseforskningsloven § 11.

Vurdering

Sekretariatet i REK har vurdert følgende endringer i prosjektet:

- Utvidelse av prosjektets sluttdato til fra 31.12.2016 til 31.12.2019. Videre analyser og skriving av vitenskapelige artikler er påbegynt og forventes å bli fullført i løpet av 2017-2019. Datainnsamlingen ble avsluttet vinteren 2015.

Sekretariatet i REK har vurdert den omsøkte endringen og har ingen innvendinger til de endringen som er beskrevet i skjema for prosjektendring.

Vedtak

REK godkjenner med hjemmel i helseforskningsloven § 11 annet ledd at prosjektet videreføres i samsvar med det som fremgår av søknaden om prosjektendring under forutsetning av at ovennevnte vilkår oppfylles og i samsvar med de bestemmelser som følger av helseforskningsloven med forskrifter.

Dersom det skal gjøres ytterligere endringer i prosjektet i forhold til de opplysninger som er gitt i søknaden, må prosjektleder sende ny endringsmelding til REK.

Av dokumentasjonshensyn skal opplysningene oppbevares i 5 år etter prosjektslutt. Opplysningene skal deretter slettes eller anonymiseres.

Opplysningene skal oppbevares avidentifisert, dvs. atskilt i en nøkkel- og en datafil. Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veileder for «Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse- og omsorgssektoren».

Prosjektet skal sende sluttmelding til REK, se helseforskningsloven § 12, senest 6 måneder etter at prosjektet er avsluttet.

Klageadgang

Komiteens vedtak kan påklages til Den nasjonale forskningsetiske komité for medisin og helsefag, jf. helseforskningsloven § 10 tredje ledd og forvaltningsloven § 28. En eventuell klage sendes til REK sør-øst A. Klagefristen er tre uker fra mottak av dette brevet, jf. forvaltningsloven § 29.

Med vennlig hilsen

Knut Ruyter
Avdelingsdirektør
REK sør-øst sekretariatet

Elin Evju Sagbakken
Seniorrådgiver

Kopi til: *kso@nlsh.no; oskjelda@vestreviken.no; inger.kari.nerheim@sus.no; kjersti.egenberg@ras.rl.no; kah@r-bup.no; siri.gjesdahl@sshf.no; trond.rangnes@ahus.no; postmottak@nlsh.no; personvern@ahus.no; postmottak@vestreviken.no; post@helse-stavanger.no; mail@r-bup.no*

Meldeskjema for interngodkjenning av forsknings- og kvalitetsprosjekter

Utfylt skjema med vedlegg sendes til: **(R) Fellesmail Personvernombud**

Meldeskjemaet skal utfylles for

1) Medisinsk og Helsefaglig forskning, og
2) Kvalitetsstudier og annen forskning enn medisinsk og helsefaglig forskning, eller
3) Intern kvalitetssikring

som omfatter mennesker og humant biologisk materiale.
Omfatter også pilotstudier og utprøvende behandling.

Råd og veiledning:
Personvernombud: marianne.blair.berg@ahus.no
Biobankkoordinator: Randi.Otterstad@ahus.no
Datafangst: datafangst@ahus.no

Mer informasjon: internettsiden til Ahus (Gå til www.ahus.no > Forskning og utvikling > Rutiner for forskning).

1 INFORMASJON OM PROSJEKTANSVARLIG OG PROSJEKTLEDER (SØKEREN)

A. PROSJEKTANSVARLIG (div. direktør / klinikksjef)

Navn og stilling: Trond Rangnes, divisjonsdirektør	Divisjon/klinikk (nivå 2): Akershus universitetssykehus, Divisjon psykisk helsevern

B. PROSJEKTLEDER[1]

Navn og stilling: Torleif Ruud, avdelingssjef / professor	Klinikk/avdeling (nivå 3) hvor prosjektet gjennomføres: Divisjon psykisk helsevern, Avdeling forskning og utvikling
Telefonnummer: 67968773 / 97546760	E-postadresse: torleif.ruud@ahus.no

C. MULTISENTERSTUDIE

Er prosjektet en multisenterstudie? ☒ Ja ☐ Nei

Dersom **ja**, angi øvrige virksomheter som deltar: Datainnsamling skjer også ved Norlandssykehuset HF, Vestre Viken HF, Sørlandet sykehus HF, Helse Stavanger HF sammen med Rogaland A-senter ved lokale prosjektgrupper. Regionsenter for barn og unges psykiske helse øst og sør (RBUP øst og sør) og Barns Beste (nasjonalt senter for barn som pårørende i helsevesenet) er også faglige parter i prosjektet.
Avidentifiserte data lagres elektronisk i database i firmaet Confirmit ved utfylling av spørreskjema på Ipad/laptop med 3G forbindelse ved opplegg som R-BUP har i samarbeid med Confirmit og som er brukt i andre studier og godkjent av REK. Ved fullført datainnsamling overføres alle data til forskningsserver på Ahus, og samarbeidspartnere får bare utlevert anonymiserte datafiler for analyser i henhold til en avtalt plan for publisering.

Skal noen av disse også ha kopi av elektronisk database/informasjon som etableres i prosjektet? ☐ Ja ☒ Nei

D. ANNEN DATABEHANDLINGSANSVARLIG ENN AKERSHUS UNIVERSITETSSYKEHUS HF[2]

Er prosjektet organisert fra et legemiddelfirma eller annen ekstern virksomhet? ☐ Ja ☒ Nei

Dersom **ja**, angi virksomhetens navn (Kopi av konsesjonen/godkjenning skal sendes personvernombudet, og prosjektet skal meldes til personvernombudet som meldepliktig prosjekt, dvs skjemaet fylles ut).

Skal den eksterne også ha kodelisten/navnelisten over deltakere? ☐ Ja ☐ Nei

2 PROSJEKTETS NAVN/TITTEL

Kort norsk tittel: Barn som pårørende.

Fullstendig tittel på engelsk: Children of patients with severe illness or substance abuse: Prevalence, identification, perceived needs, services received and outcome.

3 PROSJEKTPERIODE		
Studiestart (dd.mm.åååå): 16.05.2012	Studieslutt (dd.mm.åååå)[3]: 31.12.2015	Sletting/anonymisering av data legg til tid mht etterprøving (dd.mm.åååå): 31.12.2016 Beskriv hvordan data vil bli slettet/anonymisert: Kodenøklene hos de lokale koordinatorene makuleres/slettes. **Prosjektleder er selv ansvarlig for gjennomføring av sletting/anonymisering**

4 FINANSIERING AV PROSJEKTET

☐ Nei ☒ Ja Hvis ja – hvor (NFR, HSØ, interne midler etc): Forskningsprosjektet har fått tildelt 9,5 mill kroner fra Norges forskningsråd. Partene som deltar bidrar med et lignende beløp ved bruk av intern tid og egne midler. Det er skrevet samarbeidsavtaler mellom Ahus og de andre samarbeidspartene, og disse avtalene er undertegnet på direktørnivå.

Prosjektnr/kostnadsted: 2927011 / 70100

5 BESKRIV FORMÅLET MED BEHANDLINGEN/PROSJEKTET (lovpålagt – varierer for kvalitet og helsefaglig forskning)[4]

PRIMÆRE MÅL (1) Gi ny kunnskap om prevalens, kjennetegn ved barn av foreldre i spesialisthelsetjenesten, i hvilken grad disse barn er identifisert, andelen av disse barna som opplever problemer, hvordan de og deres foreldre opplever hjelp og oppfølging, og kurs og utfall av barna og deres familier. (2) Identifisere og beskrive behov for forbedring av identifikasjon, hjelper og oppfølging for barn av foreldre i spesialisthelsetjenesten og deres familier. SEKUNDÆRE MÅL (3) Gi innspill til forbedring av det norske systemet for identifikasjon og hjelp til barn av foreldre i spesialisthelsetjenesten og deres familier. (4) Utvikle forskningssamarbeid som kan fortsette i dette feltet, spesielt i planlegging, gjennomføring og testing av effektive tjenester for barn som pårørende og deres familier.
METODE Prosjektet er en epidemiologisk og utforskende studie med et representativt utvalg (N = 900) fra fem helseforetak som betjener 34% av befolkningen i Norge. Vi inkluderer 60 barn i hver gruppe (psykisk syke, rusmiddelmisbrukere og alvorlig somatisk syke foreldre) i hvert av de fem helseforetakene. Et stratifisert randomisert utvalg trekkes ved rekruttering av det nevnte antallet barn og foreldre i løpet av 18 måneder. Intervjuer av barn og deres foreldre ved bruk av spørreskjema vil bli gjort av godt kvalifiserte forskere, klinikere og mastergradsstudenter. Vi samler data om identifisering av barn ved de ordinære prosedyrer, og vi ønsker å gjøre en 12 måneders oppfølging studie av et underutvalg eller hele utvalget. Vi vil også samle data ved spørreskjema til lærere i barnehage/skole, og til behandlere i spesialisthelsetjenesten. Spørreskjemaene til barn, foreldre og lærere er sammensatt av godt etablerte instrumenter. Prosedyrer for identifikasjon, rekruttering og intervjuer av barn og foreldre er pilot testet og justert etter dette. En publiseringsplan med fordeling av forskningstema og publikasjoner blant stipendiater og samarbeidsparter utarbeides før starten av datainnsamlingen.

6 AVKLARING FOR KONSESJON ELLER MELDING[5]

a) Kobling

☐ Ja, det benyttes kobling mot forskriftsregulerte registre, som for eksempel fødselsregister, kreftregister eller dødsårsaksregister, eller interne konsesjonsbelagte registre.
Hvis ja, angi hvilke registre:

b) Store datasett

Angi totalt antall inkluderte:

☐ Ja, studien inkluderer et stort omfang av personer og/eller data - dvs mer enn 5000 og/eller opplysninger av svært inngripende karakter.

c) Varighet

Angi antall år opplysningene vil bli lagret, inkludert oppbevaring for etterprøving [6]: .

7 RETTSLIG GRUNNLAG FOR BEHANDLING AV PERSONOPPLYSNINGENE [7]

7.1 Samtykke

Skal det innhentes skriftlig samtykke fra den registrerte?	☒ Ja	☐ Nei
Skal det innhentes skriftlig samtykke fra andre enn den registrerte?	☐ Ja	☐ Nei
Skal det søkes om unntak fra taushetsplikten?	☐ Ja	☐ Nei

ELLER

7.2 Intern kvalitetssikring av pasientbehandling.[8]

☐ Ja, prosjektet oppfyller helsepersonelloven § 26. Opplysningene må være slettet eller anonymisert før eventuell publisering av resultater. Må publiseres som kvalitetssikring, ikke som forskning. Det kreves ikke samtykke (ref. punkt 5.1). Personopplysningsloven § 33 4. ledd gir unntak for konsesjon, men krever melding. Det er ikke krav til samtykke, men pasienter som har reservert seg mot slik bruk av opplysningene skal respekteres.

ELLER

7.3 Annet som hjemler melding, angi årsak/hjemmel:

7.4 Andre tillatelser

☒ Søknadsplik til de regionale komiteer for medisinsk og helsefaglig forskningsetikk(REK)[9]

☐ Søknadsplikt til Statend legemiddelverk

☐ Bioteknologiloven kommer til anvendelse (det uføres genetiske undersøkelser hvor deltageren gis tilbakemelding om resultatet)[10]

☐ Øvrig (se pkt 11)

8 BRUK AV HUMANT BIOLOGISK MATERIALE

BIOBANK

Medfører prosjektet bruk av humant, biologisk materiale? ☐ Ja ☒ Nei

Dersom ja:

Benyttes en allerede eksisterende biobank? ☐ Ja ☐ Nei

Hvis ja, angi:
- ☐ tematisk forskningsbiobank (basert på bredt samtykke)*
- ☐ spesifikk forskningsbiobank (basert på samtykke til et spesifikt prosjekt)
- ☐ generell biobank (legemiddelselskap som ansvarshavende)
- ☐ diagnostisk biobank
- ☐ behandlingsbiobank

Navn på biobank:

Biobankregisternr.:

* Om prosjektet skal benytte seg av materiale fra en tematisk forskningsbiobank må det innhentes godkjenning fra prosjektleder av denne.

9 DETALJER OM PROSJEKTETS INFORMASJONSBEHANDLING

9.1 Type personopplysninger behandlingen skal omfatte:

9.1.1 Ikke-sensitive personopplysninger

Identifikasjonsopplysninger

☒ Navn, adresse, fødselsdato
☐ Fødselsnummer (11 siffer)
☐ Fingeravtrykk, irirs
☐ Annet:

Opplysninger om tredjepersoner

☐ Navn, adresse, fødselsdato
☐ Fødselsnummer (11 siffer)
☐ Annet:

9.1.2 Sensitive personopplysninger (jf. personopplysningsloven § 2 nr. 8)

Prosjektet omfatter opplysninger om

☒ Rasemessig eller etnisk bakgrunn, eller politisk, filosofisk eller religiøs oppfatning
☒ At en person har vært mistenkt, siktet eller dømt for en straffbar handling
☒ Helseforhold
☐ Seksuelle forhold
☐ Fagforeningstilhørighet

Presiser nærmere: For hver familie som deltar gis det et spørreskjema til ett av barna, begge foreldrene og lærer i skole/barnehage (med samtykke fra foreldre). Spørsmålene i spørreskjemaet til barn/ungdom og foreldre gjelder livssituasjon, egen helse og fungering (foreldre spørres også om barnets helse og fungering), bruk av rusmidler, hva slags hjelp en eventuelt opplever behov for, og hva en selv eller familien har mottatt av hjelp. Lærere spørres bare om barnet/ungdommens fungering faglig og sosialt i skole eller barnehage.

9.2 Utvalg i studien

Behandlingen omfatter opplysninger om (beskriv også eventuell kontrollgruppe):

☐ Ansatt i egen virksomhet
☐ Adgangskontrollerte
☐ Elever/studenter/barnehagebarn
☐ Medlemmer
☒ Pasienter
☒ Kunder/klienter/brukere
☐ Tilfeldig utvalgte
☐ Seleksjonsutvalgte

☐ Friske frivillige

Dersom det skal gis godtgjørelse, beskriv nærmere: Hver familie som deltar mottar to kinobilletter som kompensasjon for den tiden de bruker på å svare på spørreskjemaene.

Inkluderer utvalget personer med begrenset samtykkekompetanse, eks mindreårige, demente eller annet? x Ja Nei

Dersom **ja**, forklar: Barn 8 – 18 år iflg spørreskjema

9.3 Innsamling av opplysningene

Hvordan personopplysningene samles inn (flere avkryssinger er mulig)

☒ Manuelt ☐ Elektronisk (bilde og tekst) ☐ Videoopptak ☐ Lydopptak ☐ Annet (beskriv hvordan):

Hvor innhentes personopplysningene fra?	☒ Fra den registrerte selv ☐ Annet (beskriv hvor fra):

Hvis uttrekk av forskningsdata, hvem utfører uttrekk og anonymisering/avidentifisering av data i dette utrekket[11]:

☐ Datafangstgruppen
☐ Sykehuspartner
☐ Andre – oppgi hvem (prosjektleder el andre registre, for eksempel NPR, SSB eller andre helseinstitusjoner):

9.4 Utlevering av opplysningene

Blir personopplysningene gjort tilgjengelige/utlevert til andre virksomheter? x Ja Nei

Dersom **ja**, oppgi mottakeres navn og adresse, samt hvilken rolle mottakeren har i prosjektet: .
Dersom mottaker skal være databehandler må det inngås databehandleravtale.
Er det inngått slik avtale? Dersom **ja**, legg ved avtale. ☐ Ja ☐ Nei

Hva blir overført?

☐ Informasjon med navn, personnummer eller annet som entydig angir det enkelte individ (kryptert overføring kreves)

☐ Anonymisert informasjon (ikke mulig å bakveiidentifisere)

X Avidentifisert informasjon (ikke mulig å bakveisidentifisere uten nøkkel). Forklar i såfall hvordan kryssreferanseliste beskyttes dersom dette ikke er likt som i pkt 9.6:

Hvordan oversendes informasjonen til andre virksomheter ?

☐ Personlig overlevering

☐ CD sendt med rekommandert post

☐ Legges ut på sikret område for nedlasting av mottaker (kryptert)

☐ Annet. Beskriv nærmere:

9.5 Lagring og behandling av opplysninger

Hvordan lagres opplysningene?

☒ Elektronisk

- ☒ Egen forskningsserver ved AHUS
- ☐ Annen virksomhet – oppgi hvem:
- ☐ Forskningsserver ved UiO (kun anonymiserte data)
- ☒ Annet. Beskriv nærmere[12]: Midlertidig lagring av avidentifiserte data under datainnsamlingen på server som R-BUP bruker hos Confirmit i etablert samarbeid om forskningsprosjekter.

☐ På papir. Forklar hvordan dette sikres mot uvedkommende:

☐ På video, tape eller annet opptak. Beskriv hvordan dette er sikret og om personen kan identifiseres:

☐ Annet. Beskriv nærmere:

9.6 Gjenfinning av opplysningene

Hvordan gjenfinnes opplysningene? (Bruk av direkte identifisering som personnummer og navn skal forsøkes unngått)

☐ Opplysningene lagres med navn, personnummer eller annet som entydig angir det enkelte individ

☒ Opplysningene lagres avidentifisert (ved bruk av krysslister, kodenøkkel, løpenummer eller lignende)

Hvordan er krysslister/kodenøkler beskyttet/lagret? Forklar: Kodenøkler oppbevares forsvarlig nedlåst hos lokal koordinator på hvert av de fem helseforetakene som deltar i prosjektet, og atskilt fra de data som samles inn.

10 DATO FOR UTFYLLING

Prosjektet er forelagt for og godkjent av divisjonsdir/ klinikksjef ☒ Ja. Hvem: Divisjonsdirektør Trond Rangnes

Sted og dato 12.12.2012	**Signatur (sendt fra personlig epostadresse godtas) :** Torleif Ruud, prosjektleder, FOU-avd PHV Ahus Prosjektet er godkjent av REK 08.11.12 med referansenummer 2012/1176/REK sør-øst A

11 BEHANDLING AV PERSONVERNOMBUD

Skal det sendes søknad om konsesjon til Datatilsynet?

☐ **Ja, det må sendes søknad om konsesjon til Datatilsynet, Jfr POL §33)**

X **Nei, ikke nødvendig – oppgi begrunnelse:**

REK har godkjent prosjektet, kodenøkkel forblir ved det enkelte helseforetak, kryptert linje for utfylling av skjema inn i Confirmit, og kryptert overføring til Ahus' forskningsserver. Dataene er anonyme og krypterte under mellomlagringen hos Confirmit, og databehandler ikke påkrevd. Forutsatt gjennomført som beskrevet anbefales prosjektet.

Sted og dato Nordbyhagen, 20.12.2012	**Navn personvernombud:** Marianne Blair Berg

12 GODKJENNING FOR OPPRETTELSE AV REGISTER/PROSJEKT (fylles ut av direktør ved Forskningssenteret)

Anmodning om opprettelse av forskningsregister er:

☒ **Godkjent (skjema sendes personvernombudet)**

☐ **Avslått (skjema returneres avsender)**

Sted og dato 2/1 -2013	**Navn forskningsdirektør:** Hilde Lurås

Vedlegg – kryss av hvis relevant for type studie:

☒ Protokoll/prosjektbeskrivelse
☒ Vedtak fra Regional etisk komité (REK)
☒ Pasientinformasjon / Samtykkeerklæring
☒ Spørreskjema / Intervjuguide
☐ Legemiddelstudie – Legg også ved meldeskjema til SLV

Saken kan ikke behandles hvis relevante vedlegg mangler

Merknader

---

[1] Prosjektleder er ansvarlig for at studien formaliseres i henhold til gjeldende lovbestemmelser. Hvis prosjektleder ikke er ansatt ved Akershus universitetssykehus HF (Ahus) må det oppgis navn på den Ahus-ansatte som er ansvarlig for at studien formaliseres korrekt.

[2] For alle studier som startes i regi av Ahus og som bruker pasientdata som utgår fra Ahus vil normalt databehandlingsansvarlig være Forskingsdirektør ved Ahus. Hvis det foretas en utlevering av data til ekstern institusjon, skal navnet på denne virksomheten skrives her.

[3] Når prosjektet er ferdigstilt. Dette inkluderer innsamling, analyse/vurdering, artikkelskriving/konklusjon.

[4] Behovet for konsesjon/melding er knyttet opp til hvilket formål man har med behandlingen av personopplysningene. Pasientjournalsystemet er meldt i sin helhet, og har lovhjemlet formål. Når informasjon i journalsystemet skal benyttes til andre formål må konsesjon eller alternativt ny melding vurderes og man må angi formålet med den nye bruken/behandlingen av personopplysningene. Formulering av formålet er derfor viktig. Tilsvarende gjelder for annen innsamling og behandling av pasient-/personopplysninger. Formålet må samsvare med det som beskrives i samtykket fra hver enkelt person som deltar i studien.

[5] Ett av de tre hovedpunktene under må være oppfylt for at studien skal være meldepliktig, og unntatt fra konsesjon:

1. Prosjektet er omfattet av personopplysningsforskriften §7-27. (Punkt a må være oppfylt, samt enten b eller c)
   a) Prosjektet er tilrådd av personvernombud. For prosjekter med medisinsk eller helsefaglig forskning skal prosjektet i tillegg være godkjent av REK.
   b) Ikke stort omfang, men lang varighet og identifiserbart, eller
   c) store datasett og tilfredsstillende avidentifisert eller pseudonymisert.
2. Prosjektet/behandlingen har hjemmel i lov og utføres i regi av organ i stat eller kommune (eks. kvalitetssikring etter helsepersonellovens § 26) – se personopplysningsloven § 33, fjerde ledd.
3. Prosjektet er regulert i forskrift som spesielt angir at det er unntatt fra konsesjonsplikt eller underlag meldeplikt (f.eks. de sentrale helseregisterforskriftene)

Frafallsanalyser (analyser av fordelinger over utdanning, inntekt og ytelser m.m. blant fremmøtte og ikke-fremmøtte for å beregne betydningen av frafallet) er også unntatt dersom de er basert på samtykke.

[6] Data skal lagres i en viss tid etter at prosjektet er ferdigstilt (analyse er gjennomført) for mulig etterprøving. I forskningsstudier skal data lagres 5 år (Norsk Lægemiddelforening) etter publisering, og for klinisk utprøving skal data lagres i minst 15 år etter innsendt sluttrapport til SLV. Enkelte større tidsskrifter krever 10 års oppbevaring for etterprøving. Data kan ikke oppbevares etter prosjektslutt for kvalitetssikring. Dersom forskningsprosjektet er finansiert av Norges forskningsråd, skal sluttrapport og prosjektdata arkiveres på betryggende måte i minimum 10 år etter avslutning av prosjektet (se punkt 5.3 i Norges forskningsråds generelle kontraktsvilkår).

[7] Som hovedregel skal skriftlig informert samtykke innhentes.

[8] Kvalitetssikring er intern kvalitetskontroll av diagnostiske og behandlingsmessige metoder som har som formål å forbedre diagnostiseringen og behandlingen av pasientene ved sykehuset.

[9] REK portal: http://helseforskning.etikkom.no

[10] Når det skal gis tilbakemelding om genetiske resultater skal deltagerne informeres før, under og etter det utføres genetiske analyser. Det er ikke aktuelt å gi tilbakemelding til barn.

[11] Ved prosjekt slutt er prosjektleder ansvarlig for at data blir anonymisert/slettet. Ta kontakt med datafangstgruppen (datafangst@ahus.no) hvis det er behov for bistand.

[12] Krever gjennomføring og godkjenning av risikovurdering

Appendix II

Questionnaire for children aged 8-13

Barn som pårørende

Spørreskjema for barn
8 – 13 år

Denne siden besvares av intervjuer
Når du har svart på hvem som er identifisert pasient kan du levere iPaden til barnet.

ID nummer: ____________

Dato: _____________

Hvem i familien er identifisert som pasient?
Mor: ☐ Far ☐

Spørreskjema om hvordan det er å ha en forelder som er syk eller har rusproblemer

Mange barn og ungdom opplever at foreldre blir syke eller har rusproblemer. Når en forelder blir alvorlig syk eller strever med rusproblemer vil hele familien bli berørt, også barna. Noen barn og unge synes det er vanskelig, mens andre ikke merker så mye til det.

Vi vil gjerne spørre deg om hvordan du har det når din forelder er syk eller har rusproblemer, hva du har fått av hjelp og informasjon, og hva du ønsker hjelp til. Vi skal undersøke hvordan dette er for 900 barn og ungdommer.

Dersom du synes at noen av spørsmålene er vanskelige kan du spørre oss om hjelp.

Undersøkelsen er frivillig og du trenger ikke å vise svarene dine til noen. Ingen som kjenner deg vil få se på skjemaet når du har fylt det ut.

Det tar ca. 50-60 minutter å svare på spørsmålene.

Litt informasjon om deg

Er du gutt eller jente?

Jente: ☐ Gutt: ☐

Hvor mange år er du?

☐

Hvor mange søsken har du?

Ingen: ☐ 1: ☐ 2: ☐ 3 eller flere: ☐

Hvis du har søsken, hvor mange søsken bor du sammen med?

Ingen: ☐ 1: ☐ 2: ☐ 3 eller flere: ☐

Eier familien din en bil?

Nei: ☐ Ja, 1 bil: ☐ Ja, 2 eller flere biler: ☐

Har du et eget soverom?

Ja: ☐ Nei: ☐

I løpet av det siste året, hvor mange ganger har du reist på ferie med din familie?

Ingen: ☐ 1 gang: ☐ 2 ganger: ☐ Mer enn 2 ganger: ☐

Hvor mange datamaskiner eier din familie?

Ingen: ☐ 1: ☐ 2: ☐ 3 eller flere: ☐

Informasjon og hjelp

Nå kommer noen spørsmål om hva du vet om din forelders sykdom eller rusproblemer og hva du ønsker av hjelp.

Hvor lenge har du kjent til sykdommen eller rusproblemene?

Fikk nylig vite om det: ☐ I flere måneder: ☐ I flere år: ☐ Har alltid visst det: ☐

Spørsmål om hva du vet om sykdommen eller rusproblemene

Det finnes ingen riktige eller feil svar, svar så godt du kan…	Ja	Nei	Vet ikke
Har din forelder fortalt deg om sin sykdom?	☐	☐	☐
Har en annen voksen du bor sammen med fortalt deg om din forelders sykdom?	☐	☐	☐
Har noen der din forelder får hjelp fortalt deg om din forelders sykdom?	☐	☐	☐
Har du vært på besøk der din forelder får hjelp for sin sykdom?	☐	☐	☐
Har du vært med i en samtale sammen med din syke forelder med de som gir din forelder hjelp (fagfolk)?	☐	☐	☐
Har du hatt samtale uten din syke forelder med de som gir din forelder hjelp (fagfolk)?	☐	☐	☐

Spørsmål om situasjonen hjemme

Det finnes ingen riktige eller feil svar, svar så godt du kan…	Nei	Lite	Noe	Mye
Må du ta mer ansvar hjemme når din forelder er syk?	☐	☐	☐	☐
Får du nok hjelp til skolearbeidet hjemme?	☐	☐	☐	☐
Kan du snakke med din syke forelder om ting du er opptatt av?	☐	☐	☐	☐
Er det orden i huset og klare regler hjemme hos deg?	☐	☐	☐	☐
Får du hjelp til å følge opp aktiviteter du er med i på fritiden?	☐	☐	☐	☐
Gjør familien hyggelige aktiviteter sammen?	☐	☐	☐	☐
Er familien sammen med andre utenom familien?	☐	☐	☐	☐
Når din forelder er syk, tar en annen voksen da over det ansvaret den som er syk vanligvis har?	☐	☐	☐	☐

Får du hjelp fra andre enn de du bor sammen med?

	Nei	Lite	Noe	Mye
Kjæreste	☐	☐	☐	☐
Venner	☐	☐	☐	☐
Familie	☐	☐	☐	☐
Naboer	☐	☐	☐	☐
Ledere i fritidsaktiviteter (sport, musikk, speider)	☐	☐	☐	☐

Får du hjelp fra fagfolk (mennesker som har som jobb å hjelpe andre)?

	Nei	Lite	Noe	Mye
Ekstra hjelp fra lærer / skole	☐	☐	☐	☐
Helsesøster	☐	☐	☐	☐
BUP (Barne- og ungdomspsykiatrien)	☐	☐	☐	☐
PPT (Pedagogisk psykologisk tjeneste)	☐	☐	☐	☐
Barnevernet	☐	☐	☐	☐
Barnegruppe/ungdomsgruppe	☐	☐	☐	☐
Andre	☐	☐	☐	☐
Har du opplevd at fagfolk har vært på besøk hjemme hos deg?	☐	☐	☐	☐

Hvilke andre fagfolk er det du får hjelp fra? ____________________

Hvor fornøyd er du med hjelpen du har fått fra:

	Ikke fornøyd	Middels	Svært fornøyd	Ikke aktuelt
Kjæreste	☐	☐	☐	☐
Venner	☐	☐	☐	☐
Familie	☐	☐	☐	☐
Naboer	☐	☐	☐	☐
Ledere fridtidsaktiviteter (sport, musikk, speider)	☐	☐	☐	☐
Lærer / skole	☐	☐	☐	☐
Helsesøster	☐	☐	☐	☐
BUP (Barne- og ungdomspsykiatrien)	☐	☐	☐	☐
PPT (Pedagogisk psykologisk tjeneste)	☐	☐	☐	☐
Barnevernet	☐	☐	☐	☐
Barnegruppe/ungdomsgruppe	☐	☐	☐	☐
Andre	☐	☐	☐	☐

Hvem andre er det du får hjelp fra? ____________________

Hvordan er situasjonen din nå?

Det finnes ingen riktige eller feil svar, svar så godt du kan…	Ja	Nei	Vet ikke
Vet du nok om din forelders sykdom?	☐	☐	☐
Snakker dere i familien sammen om din forelders sykdom?	☐	☐	☐
Får familien nok hjelp, slik at du kan ha det som normalt?	☐	☐	☐
Er det laget en plan for hva familien kan gjøre hvis sykdommen forverres?	☐	☐	☐
Vet du om noen du kan kontakte hvis situasjonen hjemme blir vanskelig?	☐	☐	☐

Hvem stiller mest opp for deg når din forelder er syk?

Hvis du fikk velge, hvilken hjelp ville være mest nyttig for deg nå?

Det finnes ingen riktige eller feil svar, svar så godt du kan…	Ikke viktig	Litt viktig	Ganske viktig	Veldig viktig
Hjelp hjemme til husarbeid	☐	☐	☐	☐
Hjelp til lekser og oppfølging av skolen	☐	☐	☐	☐
Hjelp til å delta på mine fritidsaktiviteter	☐	☐	☐	☐
God kontakt med min lærer om situasjonen	☐	☐	☐	☐
Mer informasjon om min forelders tilstand	☐	☐	☐	☐
En plan for hva vi skal gjøre hvis situasjonen til min forelder blir vanskeligere	☐	☐	☐	☐
En person jeg kan kontakte hvis situasjonen til min forelder blir vanskeligere	☐	☐	☐	☐
At jeg vet hvem jeg skal bo hos hvis min forelder blir innlagt på sykehus	☐	☐	☐	☐
Et hyggelig rom på sykehuset hvor jeg kan møte min forelder på en god måte	☐	☐	☐	☐
God behandling til min forelder som er syk	☐	☐	☐	☐
Hjelp til å ta vare på min forelder hjemme, når han/hun er syk	☐	☐	☐	☐
Å delta i en gruppe med andre på min alder som er i samme situasjon	☐	☐	☐	☐

Er det andre voksne i familien din som er syk eller har rusproblemer?

☐ Mor
☐ Far
☐ Fars samboer/partner
☐ Mors samboer/partner
☐ Annen voksen som du bor sammen med

Hvordan har du det?

På de neste sidene kommer det noen spørsmål om hvordan du har det.

Fysisk aktivitet og helse

Til vanlig, hvordan vil du si at helsen din er?

☐ Utmerket
☐ Veldig bra
☐ Bra
☐ Ganske bra
☐ Dårlig

Når du tenker på den siste uka...

	Ikke i det hele tatt	Litt	Ganske	Veldig	I høy grad
Har du følt deg frisk og sprek?	☐	☐	☐	☐	☐
Har du vært fysisk aktiv (for eksempel løpt, klatret, syklet)?	☐	☐	☐	☐	☐
Har du kunnet løpe bra?	☐	☐	☐	☐	☐

Når du tenker på den siste uka...

	Aldri	Sjelden	Ganske ofte	Veldig ofte	Alltid
Har du følt deg full av energi?	☐	☐	☐	☐	☐

Om deg selv, humør og følelser

Når du tenker på den siste uka,

	Ikke i det hele tatt	Litt	Ganske	Veldig	I høy grad
Har livet ditt vært bra?	☐	☐	☐	☐	☐

Når du tenker på den siste uka...

	Aldri	Sjelden	Ganske ofte	Veldig ofte	Alltid
Har du vært i godt humør?	☐	☐	☐	☐	☐
Har du hatt det gøy?	☐	☐	☐	☐	☐
Har du følt deg trist?	☐	☐	☐	☐	☐
Har du følt deg så ille/elendig at du ikke har villet gjøre noe?	☐	☐	☐	☐	☐
Har du følt deg ensom?	☐	☐	☐	☐	☐
Har du vært fornøyd med deg selv slik du er?	☐	☐	☐	☐	☐

Familie og fritid

Når du tenker på den siste uka...

	Aldri	Sjelden	Ganske ofte	Veldig ofte	Alltid
Har du hatt nok tid for deg selv?	☐	☐	☐	☐	☐
Har du kunnet gjøre de tingene du ønsker i fritiden din?	☐	☐	☐	☐	☐
Har moren/faren din hatt nok tid til deg?	☐	☐	☐	☐	☐
Har moren/faren din behandlet deg rettferdig?	☐	☐	☐	☐	☐
Har du kunnet snakke med moren/faren din når du har lyst?	☐	☐	☐	☐	☐
Har du hatt nok penger til å gjøre de samme tingene som vennene dine?	☐	☐	☐	☐	☐
Har du hatt nok penger til utgiftene dine?	☐	☐	☐	☐	☐

Venner

Når du tenker på den siste uka...

	Aldri	Sjelden	Ganske ofte	Veldig ofte	Alltid
Har du vært sammen med vennene dine?	☐	☐	☐	☐	☐
Har du hatt det gøy sammen med vennene dine?	☐	☐	☐	☐	☐
Har du og vennene dine hjulpet hverandre?	☐	☐	☐	☐	☐
Har du kunnet stole på vennene dine?	☐	☐	☐	☐	☐

Skole og læring

Når du tenker på den siste uka...

	Ikke i det hele tatt	Litt	Ganske	Veldig	I høy grad
Har du vært glad på skolen?	☐	☐	☐	☐	☐
Har du klart deg bra på skolen?	☐	☐	☐	☐	☐

Når du tenker på den siste uka...

	Aldri	Sjelden	Ganske ofte	Veldig ofte	Alltid
Har du klart å følge med på skolen?	☐	☐	☐	☐	☐
Har du kommet godt ut av det med lærerne dine?	☐	☐	☐	☐	☐

Sterke og svake sider (SDQ-Nor)

Vennligst kryss av for hvert utsagn: Stemmer ikke, Stemmer delvis eller Stemmer helt. Prøv å svare på alt selv om du ikke er helt sikker eller synes utsagnet virker rart. Svar på grunnlag av hvordan du har hatt det de siste 6 månedene eller dette skoleåret.

	Stemmer ikke	Stemmer delvis	Stemmer helt
Jeg prøver å være hyggelig mot andre. Jeg bryr meg om hva de føler	☐	☐	☐
Jeg er rastløs. Jeg kan ikke være lenge i ro	☐	☐	☐
Jeg har ofte hodepine, vondt i magen eller kvalme	☐	☐	☐
Jeg deler gjerne med andre (mat, spill, andre ting)	☐	☐	☐
Jeg blir ofte sint og har kort lunte	☐	☐	☐

Fortsetter neste side…

	Stemmer ikke	Stemmer delvis	Stemmer helt
Jeg er ofte for meg selv. Jeg gjør som regel ting alene	☐	☐	☐
Jeg gjør som regel det jeg får beskjed om	☐	☐	☐
Jeg bekymrer meg mye	☐	☐	☐
Jeg stiller opp hvis noen er såret, lei seg eller føler seg dårlig	☐	☐	☐
Jeg er stadig urolig eller i bevegelse	☐	☐	☐
Jeg har en eller flere gode venner	☐	☐	☐
Jeg slåss mye. Jeg kan få andre til å gjøre det jeg vil	☐	☐	☐
Jeg er ofte lei meg, nedfor eller på gråten	☐	☐	☐
Jeg blir som regel likt av andre på min alder	☐	☐	☐
Jeg blir lett distrahert, jeg synes det er vanskelig å konsentrere meg	☐	☐	☐
Jeg blir nervøs i nye situasjoner. Jeg blir lett usikker	☐	☐	☐
Jeg er snill mot de som er yngre enn meg	☐	☐	☐
Jeg blir ofte beskyldt for å lyve eller jukse	☐	☐	☐
Andre barn eller unge plager eller mobber meg	☐	☐	☐
Jeg tilbyr meg ofte å hjelpe andre (foreldre, lærere, andre barn/unge)	☐	☐	☐
Jeg tenker meg om før jeg handler (gjør noe)	☐	☐	☐
Jeg tar ting som ikke er mine hjemme, på skolen eller andre steder	☐	☐	☐
Jeg kommer bedre overens med voksne enn de på min egen alder	☐	☐	☐
Jeg er redd for mye, jeg blir lett skremt	☐	☐	☐
Jeg fullfører oppgaver. Jeg er god til å konsentrere meg	☐	☐	☐

Samlet, synes du at du har vansker på ett eller flere av følgende områder: følelser, konsentrasjon, oppførsel eller med å komme overens med andre mennesker?

☐ Nei
☐ Ja, små vansker
☐ Ja, tydelige vansker
☐ Ja, alvorlige vansker

Hvis du har svart **”Nei”**, hopp over de fire neste spørsmålene og gå til neste side.
Har du svart **”Ja”** i en eller annen form ber vi deg svare på de neste fire spørsmål

Hvor lenge har disse vanskene vært tilstede?

☐ Mindre enn 1 måned
☐ 1-5 måneder
☐ 6-12 måneder
☐ Mer enn ett år

Forstyrrer eller plager vanskene deg?

☐ Ikke i det hele tatt
☐ Bare litt
☐ En god del
☐ Mye

Virker vanskene inn på livet ditt på noen av disse områdene:

	Ikke i det hele tatt	Bare litt	En god del	Mye
Hjemme / i familien	☐	☐	☐	☐
Forhold til venner	☐	☐	☐	☐
Læring på skolen	☐	☐	☐	☐
Fritidsaktiviteter	☐	☐	☐	☐

Er vanskene en belastning for de rundt deg (familie, venner, lærere osv.)?

☐ Ikke i det hele tatt
☐ Bare litt
☐ En god del
☐ Mye

Noen mennesker har opplevd store påkjenninger eller skremmende hendelser som f.eks. ulykker, vold eller overgrep fra andre mennesker. Hvis dette gjelder deg, ber vi deg om å svare på de neste spørsmålene. Hvis ikke gå videre til neste del ”Hva hjelper du til med?” på neste side (side 13)

Kryss av for hvordan du har hatt det den siste uken:

	Aldri	Sjelden	Noen ganger	Ofte
Har du hatt vansker med å konsentrere deg?	☐	☐	☐	☐
Reagerer du sterkt på høye uventede lyder eller når noe uventet skjer?	☐	☐	☐	☐
Blir du lett irritabel eller sint?	☐	☐	☐	☐
Er du på vakt for ting som kan skje. Selv når du vet at det ikke er nødvendig?	☐	☐	☐	☐
Har du søvnproblemer?	☐	☐	☐	☐
Har du tenkt på det også når du ikke har villet det?	☐	☐	☐	☐
Har du forsøkt å slette det som hendte fra hukommelsen?	☐	☐	☐	☐
Har du hatt perioder med sterke følelser/minner om det som skjedde?	☐	☐	☐	☐
Har du holdt deg unna ting eller situasjoner som minner deg om det som skjedde?	☐	☐	☐	☐
Har du forsøkt å la være å snakke om det som har hendt?	☐	☐	☐	☐
Har bilder fra det som hendte dukket opp i tankene dine?	☐	☐	☐	☐
Har ting du har opplevd plutselig fått deg til å tenkte på det som hendte?	☐	☐	☐	☐
Forsøker du å unngå å tenke på det som hendte?	☐	☐	☐	☐

Hvis du vil kan du skrive her hva du har opplevd:

Hva hjelper du til med?

På de neste sidene kommer noen spørsmål om hva du hjelper til med hjemme

Nedenfor er det listet opp noen typer oppgaver som barn og ungdom gjør for å hjelpe eller ta vare på noen hjemme

Tenk på hva du har hjulpet til med den siste måneden	Aldri	Av og til	Ofte
Gjort rent rommet ditt	☐	☐	☐
Gjort rent andre rom	☐	☐	☐
Tatt oppvasken eller satt inn i oppvaskmaskinen	☐	☐	☐
Pyntet rom/ryddet rom	☐	☐	☐
Tatt ansvar for innkjøp av mat	☐	☐	☐
Hjulpet med å løfte eller bære tunge ting	☐	☐	☐
Hjulpet til med økonomiske spørsmål som regninger, tatt ut penger	☐	☐	☐
Jobbet deltid for å bidra økonomisk	☐	☐	☐
Tolket, brukt tegn eller annet kommunikasjonssystem for den personen som er syk	☐	☐	☐
Hjulpet den som er syk eller som du tar vare på med å kle av eller på seg	☐	☐	☐
Hjulpet den som er syk eller som du tar vare på med å vaske seg	☐	☐	☐
Hjulpet personen som er syk eller som du tar vare på med å bade eller dusje	☐	☐	☐
Holdt den som er syk eller som du tar vare på med selskap, for eksempel sittet med dem, lest for dem, snakket med dem	☐	☐	☐
Holdt øye med den som er syk eller som du tar vare på for å passe på at han/hun har det bra	☐	☐	☐
Tatt den som er syk eller som du tar vare på med ut, for eksempel på en spasertur eller for å treffe venner eller slektninger	☐	☐	☐
Fulgt søsken til skole/barnehage	☐	☐	☐
Passet søsken mens en annen voksen er i nærheten	☐	☐	☐
Passet søsken på egen hånd	☐	☐	☐
Passet på at den som er syk eller som du tar vare på tar medisinene sine	☐	☐	☐
Ringt eller tatt kontakt med lege eller offentlig kontor for den som er syk	☐	☐	☐
Fulgt den som er syk eller som du tar vare på til lege eller sykehus	☐	☐	☐

Opplever du at du har for mye ansvar hjemme?

☐ Sjelden eller aldri
☐ Noen ganger
☐ Ofte eller svært ofte

Hvor mange timer bruker du på å hjelpe til eller ta ansvar hjemme en helt vanlig uke?

☐ 1-4 timer
☐ 5-9 timer
☐ 10-19 timer
☐ 20-49 timer
☐ 50 timer eller mer

Hvor mange år var du når begynte å hjelpe til eller ta mer ansvar hjemme?

☐ Før fylte 9 år
☐ 10-11 år
☐ 12-13 år
☐ 14-15 år
☐ 16-18 år

Hvordan føles det å hjelpe til eller ta vare på noen?

På de neste sidene er det listet opp uttalelser fra barn og unge om hvordan det føles å ta vare på noen.   Kryss av i hvilken grad dette stemmer for deg.   Det finnes ingen riktige eller feil svar. Vi er bare interessert i hvordan det å hjelpe til virker inn på livet ditt og hvordan du har det.

Å hjelpe eller ta vare på noen gjør at:

	Aldri	Av og til	Ofte
Jeg føler at jeg gjør noe bra	☐	☐	☐
Jeg føler at jeg hjelper til	☐	☐	☐
Jeg føler meg nærmere familien min	☐	☐	☐
Jeg tenker godt om meg selv	☐	☐	☐
Jeg må gjøre ting som gjør meg opprørt	☐	☐	☐
Jeg blir stresset	☐	☐	☐

Fortsetter neste side…

	Aldri	Av og til	Ofte
Jeg lærer nyttige ting	☐	☐	☐
Foreldrene mine er stolte av meg	☐	☐	☐
Jeg har lyst til å rømme	☐	☐	☐
Jeg føler meg veldig ensom	☐	☐	☐
Jeg føler at jeg ikke holder ut	☐	☐	☐
Jeg hele tiden tenker på det jeg må gjøre hjemme	☐	☐	☐
Jeg blir så lei meg at jeg nesten ikke holder det ut	☐	☐	☐
Jeg ikke tror jeg betyr noe	☐	☐	☐
Jeg liker den jeg er	☐	☐	☐
Livet ikke synes verdt å leve	☐	☐	☐
Strever med å holde meg våken	☐	☐	☐
Jeg føler at jeg mestrer problemer bedre	☐	☐	☐
Det føles godt å kunne hjelpe	☐	☐	☐
Å hjelpe eller ta vare på noen gjør at jeg føler meg nyttig	☐	☐	☐

Ditt sosiale liv

Spørsmålene på de neste sidene handler om mange ting som barn i din alder kan gjøre. Les hver setning og tenk på hvor ofte du vanligvis gjør det som står i setningene.

Det finnes ingen riktige eller feil svar, svar så godt du kan	Aldri	Av og til	Ofte	Svært ofte
Jeg får lett venner	☐	☐	☐	☐
Jeg smiler, vinker og nikker til andre	☐	☐	☐	☐
Jeg spør før jeg bruker noe som tilhører andre	☐	☐	☐	☐
Jeg bryr meg ikke om andre elever som gjør seg til (klovner) i klassen	☐	☐	☐	☐
Jeg synes synd på andre når de opplever noe trist eller leit	☐	☐	☐	☐
Jeg sier i fra til andre når jeg er sint på dem	☐	☐	☐	☐
Jeg kan være uenig med voksne uten å krangle	☐	☐	☐	☐
Jeg holder pulten/arbeidsplassen min på skolen ryddig	☐	☐	☐	☐

Fortsetter neste side…

Det finnes ingen riktige eller feil svar, svar så godt du kan	Aldri	Av og til	Ofte	Svært ofte
Jeg deltar i fritidsaktiviteter som idrettslag eller foreninger	☐	☐	☐	☐
Jeg gjør leksene ferdig til tiden	☐	☐	☐	☐
Jeg forteller hva jeg heter når jeg treffer nye mennesker	☐	☐	☐	☐
Jeg kontrollerer sinnet mitt når noen blir sint på meg	☐	☐	☐	☐
Jeg sier i fra når jeg mener at regler er urettferdige	☐	☐	☐	☐
Vennene mine forstår at jeg liker dem, fordi jeg sier det til dem eller viser det på andre måter	☐	☐	☐	☐
Jeg hører etter når voksne snakker til meg	☐	☐	☐	☐
Jeg viser at jeg liker ros fra vennene mine	☐	☐	☐	☐
Jeg lytter til vennene mine hvis de snakker om problemer de har	☐	☐	☐	☐
Jeg nekter å bli med på noe som de voksne blir sinte for	☐	☐	☐	☐
Når jeg er uenig eller krangler med foreldrene mine, så blir jeg enig med dem til slutt	☐	☐	☐	☐
Jeg skryter av andre når jeg synes de har gjort noe bra	☐	☐	☐	☐
Jeg følger med når læreren underviser	☐	☐	☐	☐
Jeg blir ferdig med arbeidsoppgavene på skolen når jeg skal	☐	☐	☐	☐
Jeg prøver å komme i snakk med de andre i klassen (når vi får lov til å snakke sammen)	☐	☐	☐	☐
Jeg takker voksne når de har gjort noe for meg som jeg er glad for	☐	☐	☐	☐
Jeg gjør det læreren ber meg om	☐	☐	☐	☐
Jeg prøver å forstå hvordan vennene mine har det når de er sinte, fortvilte eller lei seg	☐	☐	☐	☐
Jeg spør om vennene mine kan hjelpe meg når jeg har problemer	☐	☐	☐	☐
Jeg blåser i om andre barn erter meg eller kaller meg ting	☐	☐	☐	☐
Jeg godtar at mennesker er forskjellige	☐	☐	☐	☐
Jeg bruker tiden min til hobbyer og andre interesser jeg har	☐	☐	☐	☐
Jeg spør om de andre elevene vil være med på det jeg driver med (for eksempel leker, spill eller andre aktiviteter)	☐	☐	☐	☐
Jeg snakker vanlig og rolig i diskusjoner i klassen	☐	☐	☐	☐

Fortsetter neste side

Det finnes ingen riktige eller feil svar, svar så godt du kan	Aldri	Av og til	Ofte	Svært ofte
Jeg ber voksne om hjelp hvis andre barn forsøker å slå meg eller dytter	☐	☐	☐	☐
Jeg diskuterer med de andre elevene hvis vi har et problem eller er uenige	☐	☐	☐	☐

Hva kan du påvirke?

De neste spørsmålene handler om hva du tenker du kan påvirke eller ikke

Det finnes ingen riktige eller feil svar. Svar så godt du kan.	Ja	Nei
Tror du at du kan gjøre noe så du ikke blir forkjølet?	☐	☐
Er noen mennesker bare født heldige?	☐	☐
Får du ofte skylden for ting som ikke er din feil?	☐	☐
Tror du at hvis noen jobber hardt nok kan han eller hun klare seg bra i alle fag på skolen?	☐	☐
Synes du at det nesten alltid er vanskelig å endre en venns mening?	☐	☐
Synes du at en av de beste måtene å håndtere de fleste problemer på er å ikke tenke på dem?	☐	☐
Føler du ofte at det ikke spiller noen rolle om du gjør lekser eller ikke?	☐	☐
Har du noen gang hatt en lykkeamulett (lykkebringende objekt)?	☐	☐
Føler du at du stort sett kan endre det som skjer i morgen med hva du gjør i dag?	☐	☐
Tror du at folk kan oppnå det de vil, hvis de bare fortsetter å prøve?	☐	☐
Føler du at når gode ting skjer, så skjer på grunn av hardt arbeid?	☐	☐
Føler du at når noen ikke liker deg, er det lite du kan gjøre ved det?	☐	☐
Føler du ofte at det er nesten nytteløst å prøve å bli flink på skolen fordi de fleste andre elever rett og slett er smartere enn du er?	☐	☐
Er du en type person som mener at planlegging gjør at ting kan utvikle seg til det bedre?	☐	☐

Til slutt

Vi ber deg svare på tre spørsmål med dine egne ord.

Hva har du opplevd som vanskeligst når din forelder har vært syk eller hatt rusproblemer?

Har du et råd til andre barn og unge som har en forelder som er syk eller har rusproblemer?

Er det noe vi ikke har spurt om, som du ønsker å fortelle oss?

Tusen takk for at du tok deg tid til å svare på spørsmålene! ☺