Life situation when your partner has substance use problems: Quality of life and everyday experiences

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“Grab your ticket and your suitcase
Thunder's rolling down the tracks
You don't know where you're goin' now
But you know you won't be back
Darlin' if you're weary
Lay your head upon my chest
We'll take what we can carry
And we'll leave the rest
Big wheels rolling through fields
Where sunlight streams
Meet me in a land of hope and dreams.”

Bruce Springsteen

Summary

Background

Substance use problems (SUPs) in a family member have a highly negative impact on both the person experiencing such problems and his or her relatives. An estimated 10–30% of people are affected by SUPs in a close family member. Several studies have been conducted on relatives of people with SUPs, and they have documented strains such as physical and mental health problems, isolation, lack of support, and disturbance of family routines. However, the partners of people with SUPs seem to have been studied mostly from a psychological perspective, using personality pathology as a model to explain them remaining in such a dysfunctional relationship. Furthermore, partners in these families have received limited attention from research as well as from health and social services, and the social and cultural contexts that these family members live in might have been ignored. This seems to particularly be the case if the partner cares for children alongside the person with an SUP. In Norway, legislation and guidelines impose on health and social services that relatives should be included and involved when a family member has an SUP, as well as receive support if they have substantial care tasks or burdens. To inform and include the partners of people with SUPs according to these legislations and guidelines, as well as to be able to identify their specific support needs, focusing on their life situation, quality of life (QoL), and everyday experiences is crucial.

Aim

The overall aim of this thesis was to investigate the life situation of partners to people with SUPs by examining their QoL and exploring their everyday experiences.

Methods

A mixed-methods design was employed. *Study I* employed a cross-sectional design using statistical analysis methods with questionnaire data collected from 213 partners of patients referred to treatment units for substance use disorders, mental illness, or severe physical illness (i.e., cancer or neurological conditions). *Study II* employed a scoping-review design in which nine studies were included. A five-stage framework for conducting scoping reviews and a qualitative content method were used to analyze the results. *Study III* employed a qualitative, descriptive, and explorative design as well as an inductive thematic-analysis method. Data were collected from

interviews with 10 partners of people with SUPs, and the combined results from *Studies I*, *II*, and *III* were analyzed, assembled, and reported using mixed methods.

Main findings

The mean QoL score of the partners to patients referred for treatment (*Study I*) was similar to that of a general population sample; however, 13% of the sample had a markedly low QoL. For the partners in *Study I*, perceived family cohesion was positively associated with QoL, whereas psychological distress (Symptom Checklist-10) was negatively associated. The model explained 56% of the variance in QoL. When the knowledge of QoL in partners of people with SUPs was investigated in a scoping review (*Study II*), only three of the included studies were conducted among partners exclusively. A majority of the included studies found lower QoL in the partners than in the general population, with substance use by the person with an SUP having the greatest impact on QoL among all evaluated factors. Three of the included studies reported that more than half of the partners had minor children in the household. The included studies used established and generic QoL instruments based on various conceptual and theoretical perspectives on QoL, often adapted to patients or relatives in general. When everyday experiences of partners of people with SUPs were explored (*Study III*), sharing lives (including parenthood) with partners with SUPs affected every part of the participants' lives, including their parental role. The overall theme of "Being stuck on an unsafe and unpredictable rollercoaster," was explored through three main themes: "relational strains," "stigma, shame, and lack of support," and "searching for hope and meaning." Many participants had experienced a change in their situation after gaining some distance from the SUP, either through their partner's recovery or by leaving him or her. As a result of the negative impact of their circumstances on their everyday lives, many of these individuals might require support to handle the challenges they face; however, they found it difficult to ask for help from others for fear of stigma. Thus, peer support groups are essential for enabling them to find a way out of their situation.

When the results from *Studies I*, *II*, and, *III* were combined using mixed methods at the reporting stage, a comprehensive understanding of the findings was as follows. The person with an SUP receiving treatment may have a positive impact on the partner's QoL (*Study I*); furthermore, support from peer groups may have a positive impact on his or her QoL (*Study II*) as well as affect their everyday experiences positively (*Study III*). However, psychological distress had a highly negative impact on their QoL (*Study I).* Nonetheless, when partners were allowed sufficient time for reflection during an interview (*Study III*), they elaborated extensively on parenting and ongoing concerns about their children. Despite superior perceived QoL when their partners were in treatment or they experience distance from the SUPs some other way, they remain a vulnerable group that is likely to need support. Thus, a particular focus should be placed on the dilemmas and challenges the partners of people with SUPs face as parents.

Conclusions

Because of the life situation of partners to people with SUPs, their QoL and everyday experiences are negatively affected, including their parental role. Obtaining distance from the SUP seems to be essential to be in a position to achieve an improved situation. The partners of people with SUPs require support to handle the massive strains and dilemmas they face; however, they find asking for help difficult because of the fear of stigma. Health and social services should include partners in the treatments and follow-up of individuals with SUPs. These partners should receive particular focus when they share parenthood of children, and furthermore, they should be provided information about relevant peer support groups. In addition, they should be included in the development of national guidelines based on larger scale research. A need exists for more research on partners who are parents to minor children because their situation of living with a partner with an SUP may affect their parenting.

Norsk sammendrag

Bakgrunn

Rusmiddelproblemer hos et familiemedlem har betydelige negative konsekvenser, både for den som selv har problemet, og for de pårørende. Omlag 10 til 30 prosent mennesker berøres av rusmiddelproblemer hos et nærstående familiemedlem. Det har vært gjennomført flere studier blant pårørende til personer med rusmiddelproblemer, som viser at de er utsatt for belastninger. Disse kan være fysiske og psykiske helseproblemer, isolasjon, mangel på hjelp og støtte, samt forstyrrelser i familierutiner. Studier som omfatter partnere til personer med rusmiddelproblemer har for det meste sett på psykologiske perspektiver. Personlighetspatologi har da ofte blitt brukt som en forklaringsmodell på hvorfor de forblir i et dysfunksjonelt forhold med en partner med rusmiddelproblemer. Partnere i disse familiene har fått begrenset forskningsfokus, noe som også ser ut til å gjenspeiles i helsetjenestene. Den sosiale og kulturelle konteksten de lever i kan også ha blitt oversett. Dette ser og ut til å være tilfelle når partneren har omsorg for barn sammen med vedkommende som har rusmiddelproblemer. Norske lover og retningslinjer pålegger helse- og sosialtjenestene å inkludere og involvere pårørende når et familiemedlem har rusmiddelproblemer, samt å gi dem støtte dersom de har store omsorgsoppgaver og/ eller belastninger. For å informere og inkludere partnere til personer med rusmiddelproblemer i tråd med lovverk og retningslinjer, og for å kunne identifisere deres behov for hjelp og støtte, er det viktig at det blir satt et søkelys på deres livssituasjon, deres livskvalitet og deres hverdagserfaringer.

Hensikt

Den overordnede hensikten med denne PhD-avhandlingen var å undersøke livssituasjonen hos partnere til personer med rusmiddelproblemer. Dette har blitt gjort ved å undersøke og utforske livskvaliteten og hverdagserfaringene deres.

Metode

Et ”mixed methods” design ble brukt. *Studie I* hadde et tverrsnittstudie-design. Data fra spørreskjema samlet inn blant 213 deltakere ble analysert statistisk. Deltakerne var partnere til pasienter som var til behandling i spesialisthelsetjenesten, ved henholdsvis enheter i tverrfaglig spesialisert rusbehandling (TSB), psykisk helsevern, eller alvorlig somatisk sykdom (kreft eller alvorlig nevrologiske sykdommer). *Studie II* hadde et ”scoping review design” hvor ni artikler ble inkludert.

Resultatene ble analysert ved hjelp av et femtrinns rammeverk tilpasset ”scoping reviews”, i tillegg ble det brukt kvalitativ innholdsanalyse. *Studie III* hadde et kvalitativt, deskriptivt og utforskende design, hvor det ble brukt induktiv og tematisk analysemetode. Data ble samlet inn fra intervjuer med ti partnere til personer med rusmiddelproblemer. I avhandlingen ble resultatene fra studie I, studie II og studie III analysert, sammenstilt og rapportert ved hjelp av ”mixed methods”.

Hovedfunn

Gjennomsnittsskår på livskvalitet hos partnere til pasienter i behandling *(studie I)* var samsvarende med normalbefolkningen. Tretten prosent av disse partnerne rapporterte imidlertid en markert lav livskvalitet. Videre rapporterte partnerne i *studie I* at familiesamhold var positivt assosiert med livskvalitet, mens psykologisk symptombelastning var negativt assosiert med livskvalitet. Denne modellen forklarte 56 prosent av variansen i livskvalitet. Da kunnskapsstatus om livskvalitet hos partnere til personer med rusmiddelproblemer ble undersøkt, var det kun tre av de inkluderte artiklene som utelukkende omhandlet partnere. De fleste av de inkluderte artiklene viste at livskvaliteten hos disse partnerne var lavere enn i den generelle befolkningen. Av de undersøkte faktorene var det rusbruk hos «den andre partneren» som i størst grad påvirket livskvaliteten. Tre av de inkluderte artiklene rapporterte at mer enn halvparten av partnerne bodde sammen med barn. De inkluderte artiklene hadde brukt etablerte og generiske spørreskjema om livskvalitet, men disse var basert på forskjellige konseptuelle forståelser og perspektiver på livskvalitet. Dessuten var de ofte tilpasset pasienter eller pårørende generelt. Da partnere til personer med rusmiddelproblemer ble utforsket kvalitativt *(studie III),* kom det frem at den andres rusmiddelproblemer berørte alle områder i livet, inkludert foreldrerollen. Dette ble beskrevet som «Å sitte fast i en utrygg og uforutsigbar berg- og dalbane». Temaet ble utdypet gjennom tre hovedkategorier: «relasjonelle belastninger», «stigma, skam og mangel på støtte» og «søken etter håp og mening». Som et resultat av de negative innvirkningene på alle sider ved hverdagslivet, har disse partnerne behov for støtte til å håndtere utfordringene de står ovenfor. Mange av partnerne opplevde en forandring i livssituasjonen etter å ha fått en distanse til rusmiddelproblemene, enten ved at partneren med rusmiddelproblemer fikk behandling, eller ved at de forlot ham eller henne. Imidlertid kom det fram at de uansett fant det vanskelig å be om hjelp, blant annet av frykt for stigma. Selvhjelpsgrupper ser ut til å være essensielle for at de skal klare å finne en vei ut av situasjonen.

”Mixed methods” ble brukt for å se resultatene fra *studie I, studie II* og *studie III* i sammenheng. Dette ble gjort ved rapporteringsstadiet, for å få en mer overordnet og helhetlig forståelse av resultatene. Følgende kom da frem: Det at personen som har rusmiddelproblemer får behandling, kan ha en positiv innvirkning på partnerens livskvalitet *(studie I)*. I tillegg kan en støttegruppe være til hjelp, noe som kan ha positiv innvirkning på deres livskvalitet *(studie II)* og mer positive opplevelser av hverdagserfaringene (*studie III).* Likevel vil en psykisk symptombelastning hos disse partnerne kunne føre til betydelig negativ innvirkning på livskvaliteten deres. Når partnerne i *studie III* fikk mulighet til refleksjon i form av å bli intervjuet om hverdagslivet sitt, utdypet de særlig om det å være foreldre, og om en stadig pågående bekymring for barna. Selv om de kan oppleve en god livskvalitet i en tid hvor den andre forelderen er i behandling, eller de på annen måte får en distanse til rusmiddelproblemene, så er disse partnerne en sårbar gruppe. De har sannsynligvis et behov for støtte, både for egen del og for barnas del.

Det må legges til rette for at de får nødvendig støtte for egen del, og da med et særlig fokus på de dilemmaer og utfordringer de opplever som foreldre når den andre forelderen har et rusmiddelproblem.

Konklusjon

Livssituasjonen når man er partner til en person med rusmiddelproblemer påvirker livskvalitet og berører hverdagserfaringer, inkludert foreldrerollen. Det å få en avstand til rusmiddelproblemene ser ut til å være essensielt for å komme i posisjon til å forbedre livssituasjonen. For å takle de massive belastningene og dilemmaene de står i, har disse partnerne behov for hjelp og støtte. Imidlertid synes de det er vanskelig å be om dette fordi de er redde for å bli stigmatiserte. Helse- og sosialtjenestene bør inkludere partnere ved behandling og oppfølging av personer med rusmiddelproblemer. Partnerne bør vies et spesielt fokus når de har omsorg for barn. Videre bør partnere tilbys informasjon om relevante støttegrupper. De bør også inkluderes i utviklingen av nasjonale retningslinjer som er basert på forskning i større skala. Det er nødvendig med mer forskning blant partnere som er foreldre til mindreårige barn. Dette fordi deres livssituasjon med rusproblemer hos den andre partneren også kan virke inn på det å være forelder.

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Bente Birkeland

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List of papers

Study I:

Birkeland, B., Weimand, B. M., Ruud, T., Høie, 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.

Study II:

Birkeland, B., Foster, K., Selbekk, A. S., Høie, M. M., Ruud, T., & Weimand, B. (2018). The quality of life when a partner has substance use problems: a scoping review. *Health and Quality of Life Outcomes, 16*(1), 219.

Study III:

Weimand, B., Birkeland, B., Ruud, T., & Høie, M.M. “It’s like being stuck in an unsafe and unpredictable roller coaster” – experiencing substance use problems in a partner. (submitted).

Abbreviations

ARA	Department for substance abuse and addiction treatment (Avdeling for rus- og avhengighetsbehandling)
CAGE-AID	The CAGE Questionnaire Adapted to Include Drugs
FACES-III	The Family Cohesion Subscale
ISEL	The Interpersonal Support Evaluation List
QoL	Quality of life
QoL-5	Quality of Life 5 questionnaire
SCL-10	The Hopkins Symptom Checklist 10
SSHF	Sørlandet sykehus
SUD	Substance use disorder
SUP	Substance use problem

1. Preface

My clinical work has for years been in a unit at a public hospital's treatment institution for substance use disorders (SUDs); [ARA; in English: Addiction Department, Sørlandet Hospital], which has a treatment model that includes an integrated family perspective with a psycho-educative approach (1). As a part of their treatment, patients enrolled in this unit are encouraged to invite their family members to a four-day psycho-educative session. Psychoeducation refers to the process of providing education and information to those seeking or receiving mental health services, such as people diagnosed with serious conditions (herein SUDs) and mental health conditions (or life-threatening/terminal illnesses), and their family members (2). After treatment, patients follow an 11-month aftercare program. Their family members are however discharged after the four-day family program, with a further referral to other outpatient treatment units for family care if needed. They are nevertheless recommended to attend peer support groups for relatives. Partners to patients with SUDs often expressed a need for further follow-up or therapy. The common experience among partners seemed however to be that, during their life as relatives to partners with substance use problems (SUPs) and/or subsequent SUDs, they had not been offered much attention.

Later, I held a position as educational leader in a research unit at ARA. This research unit has over the last decade conducted several studies concerning broader outcomes than abstinence from drugs or alcohol, such as quality of life (QoL). In addition, it has prioritized SUP consequences on children and other family members as a research area. This priority is based on a review stating that a family perspective in treatment has been shown to have a positive impact on persons with an SUP/SUD as well as their family members (3). It is further based on the fact that the family members may also need support for their own sake (1, 4).

During my work in both projects (as well as through my clinical background), I became increasingly concerned with the perspectives of partners to patients with an SUP. They seemed to have complex lives, with expectations to fulfill many roles during their partners' active addiction, for example being parents to small children. Several initial literature searches appeared to confirm that partners constitute a group that had only to a small degree been studied exclusively, especially regarding studies with broader focuses than pathological personality issues, burdens, and depressions.

Although they are not necessarily ill, partners often appear to encounter challenges in life, which may concern health or other areas. In my view, an important starting point is hence to investigate partners’ life situation in a broad sense: with a specific focus on their perceived QoL and their everyday experiences. This dissertation, which includes partners, and a focus on parenting when appropriate, addresses this starting point.

2. Background

2.1. Definition of substance use problems (SUPs)

An estimated 10-20% of the general population in Norway experiences SUDs during their lifetime (5). “Substance use disorder” can be used as a collective term for the harmful use of substances and substance use dependency or addiction. This includes a strong craving for substances, difficulty in controlling substance use, and continued use despite harmful consequences (5, 6). Harmful use is often called substance abuse, which causes physical or mental health damage, social and/or interpersonal problems, neglected major roles, and/or legal problems (6).

In what follows, I use the term SUP as a collective term, including SUD as well as the harmful and problematic use of substances (7-9) such as alcohol, opioids, cannabis, amphetamine/met-amphetamine, and addictive drugs/medicines (5, 6).

For a person with an SUP, there is often a complex interaction between biological, psychological, and social consequences (10). When an SUP goes further than the diagnosis criteria described in DSM-V (6), it refers to the impact of SUPs and is therefore defined broadly (11). The rationale for this is that close relatives may perceive the substance use as problematic even though the condition may not have been diagnosed (12). The consequences for relatives, including partners, do not concern the amount of substances used, but rather how and to what extent the use of substances affects both the person with an SUP and that person’s relationships with his or her closest relatives (13). It is however important to underline that although this thesis focuses on partners, it does not intend to advocate for partners at the expense of persons with an SUP. Partners seem to be disempowered through their close relationship with persons with SUPs, who in turn are disempowered through their SUP (14).

2.2. Partners to persons with an SUP

An estimated 10-30% of people are affected by a close family member’s SUP, based on prevalence studies in Norway (15), Ireland (8), and Australia (7). The negative impact of SUPs on various areas of relatives’ lives has been well documented for decades (16-19), but partners appear to be a group of relatives that has received limited attention in research. This seems to be the case particularly if the partner cares for children along with the person with an SUP.

Partners’ life situation in this thesis consists of their QoL and everyday experiences, including health conditions and support, family life, and social life and support. These areas are accounted for in the following subchapters.

2.2.1. Health conditions and health support

Having a partner with a chronic condition may raise specific concerns and worries about the future, which in turn can lead to stress, fatigue, and sleep deprivation (20). The specific group comprising partners to persons with SUP may for example experience violence while living together with the SUP-afflicted person. Both mental and physical health problems have been reported, such as anxiety and depression (21), and poor physical condition due to violence-related injuries (21, 22). According to Benishek et al. (22), health problems appear to be greater for female than for male partners. In addition, a great source of worry in having a partner with an SUP is often a possible effect on children, including the possibility of violence and neglect, or concern for children’s long-term wellbeing (11). Several studies also found that partners themselves reported an increased use of drugs or alcohol (18) compared to the general population (21). Studies among partners examining these health issues from a broad perspective seem to have been conducted only to a limited degree (21).

Despite the fact that a family perspective has for years been considered in both the World Health Organization’s (23) and Norwegian legislation and guidelines (24-27), several established “truths” or myths have over many years been established concerning partners to persons with an SUP (11, 28). For example, according to Orford et al., female partners have for decades been described in psychopathological and unsympathetic terms (11). This tradition is built upon the assumption that wives’ pathological personality “fits” in a dysfunctional relationship with an addictive male partner, whereby the female partner undermines any attempt by the male partner to recover from addiction (29). Male partners to females with an SUP have been stereotyped as men who show little interest in their partner’s problems and lives, and leave at the first opportunity (30).

The term “codependency” has a history of being used categorically to confirm such a dysfunctional psychopathology, which according to several studies includes the understanding of a partner as someone who enables a person’s continued SUP (30-32). Such an understanding has however been nuanced and dissociated from a pathological understanding, which has been replaced by the notion that having a problem is not the same as being the problem (32). Codependency has eventually been described as a state of being limited, in conscious awareness of one’s own emotions (33), or experiencing existential problems with a lack of sense of self (34). According to several studies conducted by Orford et al. (30, 35, 36), there nevertheless seems to have been an overall focus on psychological or intra-family conditions, thereby ignoring the family’s social and cultural context, in the absence of a broader and non-pathological perspective on the situation of partners to people affected by an SUP (30).

Ultimately, a broad perspective on family members’ SUPs generally considers relatives as ordinary people who are exposed to very stressful circumstances and severe conditions (11). Investigating how this relates to partners’ QoL and everyday experiences is important, especially as the former psychopathological understanding of these partners may have neglected or stigmatized them in the context of various health and social services (11, 28).

2.2.2. Partners’ family life

Families’ everyday life when one partner has an SUP may involve a change of roles: as one person develops an SUP, others take over his or her responsibilities, such as finances, raising children, and housework. Family routines are also disturbed, as the main focus often goes to the person with an SUP, for example on behalf of children (37, 38). When behavior in the person with an SUP becomes unpredictable, this creates difficulties for families in planning or committing to routines, for instance regarding when the person with an SUP will arrive at home and in which condition, and whether he or she will remember to pick up the children from school (37). Partners often struggle to maintain minimal family routines in their daily life, which is often considered necessary to protect minors in the family (39).

A review focusing on children’s perspectives found that when one parent suffered from an SUP, the parenting skills in the family were seriously affected by the parental SUP (40). A later study examining children’s experiences with the other parent when one of the parents had an SUP found that although some children considered the other parent as a source of support, help, and protection, many challenges seemed to reduce his or her ability to protect them. For example, the children experienced that their other parents did not receive support as the social services seemed to rely on their ability to deal with the situation. Further, conflicts with the SUP-afflicted parent after a divorce were found to form obstacles in protecting the children (41). Such strains may affect non-SUP parents’ lives in many ways. They may, according to their children’s experiences, strive to find a balance between protecting their children and maintaining contact with the SUP-afflicted parent, especially when they have a legally shared parental responsibility (41).

Bancroft et al. concludes in a review that more studies are needed among non-SUP family members, such as partners who have other roles to fulfill, and that such studies should focus on these parents’ views and roles, from their perspective (40). Later studies confirm that there is still a need for research to focus on this group in particular (21, 42). In investigating the life situation of partners to persons with an SUP, it is therefore key to focus on their everyday experiences.

2.2.3. Social life and support

Those who live close to a person with an SUP may be inclined to participate in social relationships with the SUP-afflicted person because they do not know in which condition he or she might be (e.g., affected by or recovering from the use of substances). A limitation of social life is often associated with the experienced stigma attached to substance abuse by their loved one (43, 44), in which case. Partners in this case often exclude themselves from social life, trying to hide the situation from others (39), and feel their social network does not understand the complex and sometimes abnormal and embarrassing situation they experience in their relationship with their partner (9, 33, 39). The social support partners experience may affect their life situation, including their QoL. The quality of such support is thought to be important and includes various types of support, for example emotional, informational, and material support (28), but such practices seem to a small extent to be focused on in clinical settings (45).

To my knowledge a minority of existing studies report on social life experiences among partners exclusively, with even fewer studies investigating social support. There seems thereby to be a need for studies that also investigate the perceived and experienced social support in this particular population.

2.3. Quality of life

As partners to persons with an SUP have to a large degree been studied from psychological perspectives, with personality pathology serving as a model to explain why they remain in a dysfunctional relationship with an SUP-afflicted partner (11, 35), there is a need for studies that investigate partners from broader perspectives. The QoL concept broadly encompasses how individuals measure their wellbeing regarding multiple aspects of their life (46). In studying and exploring the QoL of partners to people with an SUP, it is important to base the research on how they experience and report their QoL (subjectivity). Additionally, it is appropriate to study their QoL based on the fact that although they may experience heavy strains and their health and wellbeing may be at risk, they are not necessarily ill.

2.3.1. Multidimensional QoL

According to a review by Barcaccia et al., a large number of definitions of QoL exist, and consensus on a definition has thus far been difficult to achieve (47). Ventegodt et al. (2003) claim in their definition that “Quality of life resides in the full expression of the potentials of life” (48). According to Barcaccia et al. (47), a broad, multidimensional perspective on QoL, including at least the mental and physical health domains, as well as the relational, social, and existential domains, is appropriate in studying QoL.

In measuring “the good” and “the bad” life, there has been a shift from posing single questions about health problems or happiness to examining more complex measures in which feelings, assessments, and actions are considered (49). A multidimensional perspective on QoL can thereby include both “how we are” and “how we deal with it.” An integrative understanding of QoL has been described as one that considers how life is experienced regarding one’s own expectations, feelings, and ideas (subjective), how life is experienced “from the outside” (objective), and how life is experienced on a deeper level (existential) (50).

Subjective and multidimensional QoL includes both *hedonic* emotions and *eudaimonic* perspectives (51). Hedonism has its origins in ancient Greece, when happiness could be measured as the sum of wellbeing and discomfort or pain. This perspective is currently described as positive effect, negative effect, and satisfaction (52). Eudaimonia is a term derived from Aristotle (53) and eudaimonic QoL means self-realization, which involves vitality, commitment, and meaning. Within the traditional QoL research area, eudaimonic QoL according to Barstad (49) differs from hedonic QoL: while hedonic feelings are perceived as a result of achieving what one wants, eudaimonic feelings come from activities associated with self-realization and virtues. These activities have self-realization as their goal: obtaining vitality, commitment, meaning, and wholeness. The good life requires activity and effort, together with the acquisition of both skills and knowledge. For example, people who experiences major challenges, be it with their own or another’s illness, can still experience undertaking meaningful and engaging tasks. On the other hand, there are probably limits in real life to how meaningful a person may find it to be sleepless for a long time, for instance as a result of worrying about a partner with an ongoing SUP. This may be regardless of how meaningful the non-SUP partner otherwise experiences everyday life to be.

However, according to Martinsen et al. (54), various studies advocate for emphasizing eudaimonia to a greater extent. This is because focusing on life goals that are consistent with one’s inner possibilities can help to focus on individual skills rather than symptom treatment (51, 55). For example, research has shown that relatives of persons with SUP find it meaningful to use their experiences to obtain and provide support together with others in mutual aid support groups (33, 56). In examining QoL, existential dimensions such as meaningful life (57) and/or relation to self (50) should be included. These should be added to objective dimensions, which include the external and easily detectable areas of life, and subjective dimensions, the assessment of which is based on one’s own experiences, feelings, and ideas of “the good life” (50).

2.3.2. Quality of life measures

The number of studies investigating QoL has escalated in recent years. Measures of QoL have been used in many different disciplines such as medicine/health and the social sciences. Various QoL measures are thus based on different theoretical frameworks.

According to a review from 2006 (58), the terms QoL, health status, and functional status have however been used interchangeably, based on the premise that a fully healthy life is identical to a high QoL.

In medicine, for example, QoL represents outcomes that often play an important role in assessing the efficacy of a specific drug treatment. These QoL instruments may not measure the effect of negative side-effects, but they can detect the positive effects of treatment on health status (59). Evidence-based medicine has however traditionally measured the effectiveness of treatments without taking into consideration which sort of mechanism is involved in causing an alteration in someone’s QoL (60).

As for the social sciences, objective measures on financial status such as income or occupation have been used to measure living conditions in a population

(49). Nevertheless, in order to capture a broader perspective on a population's wellbeing, QoL is considered also in the social sciences to be an important outcome (61) in an increasing number of countries (https://ec.europa.eu/eurostat/cache/infographs/qol/index_en.html). In Norway, The Norwegian Directorate of Health has recently published national recommendations for measuring QoL (62).

Ultimately, there seems to be consensus that QoL first and foremost should be a patient- or person-reported outcome (PRO) (63) and moreover that subjectivity is thereby a core concept in studying QoL (47, 64).

Specific QoL instruments are usually developed to detect specific health conditions or treatment effects. Generic QoL measures however focus on QoL in general and not on specific conditions such as diagnosis (65). They are considered to be important in comparing different population groups (63, 66). Generic measures may thereby be useful in comparing the QoL of a vulnerable group and that of a normative population. However, in aiming at the right target, i.e., to capture the QoL perceived by the individual, such measures may to a limited degree capture the QoL of specific population groups that seem to be understudied (64).

Studies investigating the QoL of partners to persons with SUP seem to have been conducted to a limited degree. An initial search in two databases (PsycInfo and EMBASE) using relevant search terms from the SUP field, input from research colleagues, specialist literature, and controlled vocabulary such as MeSH and EMTREE, rendered four studies investigating QoL among relatives to persons with SUP, including partners. Further, the participants in the four studies reported a lower QoL compared to the general population. Only one of these studies, an American survey from 2007, was conducted among partners exclusively (21). The participants were limited to female partners to persons with SUP. In addition to a significantly lower QoL compared to the normative population, the study reports that half of the female participants had minors living in the household. The study concludes that there is a need for future research to focus on SUP partners in families with children. To my knowledge, such studies have not yet been conducted.

2.4. Rationale for a family focus in times of SUP

The World Health Organization has since 1978 stated that when there is an illness in a family, health services at all levels should dedicate attention to the family setting as a means of ensuring family health care (23). In Norway, there has been a formerly established practice for seeing patients, relatives, and children separately, but new legislation and guidelines increasingly incorporate a family perspective when a person has an illness, herein an SUD (4, 24, 25, 27), stating that relatives (including partners) should be included and involved when a family member is ill, as well as be provided with general information and/or guidance if needed.

However, including relatives according to the Patients' Rights Act (26) requires the patient's consent, which for various reasons is not always given (9, 67). It is important to emphasize that although legislation and guidelines incorporate a family perspective, this does not mean that adults and children are granted similar rights by law. Health and social services may have a culture of focusing mainly on the patient (68), which may still have constraining implications for relatives' inclusion in clinical practice, despite recent legislation.

A lack of inclusion of relatives in clinical practice may also occur because the family-oriented approach (in health or social services in which persons with an SUP [including SUD] receive treatment or support, respectively) is interpreted as being less effective at an organizational level, which stands in contrast to the fact that family-oriented practices are therapeutically effective (45). Building a culture that incorporates an overall family focus in health and social services is required in order to succeed in such approach (69).

In order to follow the laws and regulations, a stronger focus should therefore be developed on the family as a whole when one family member has an SUP. In addition to specialist health services, this focus should also include relevant health and/or social services at the municipal level (67). This perspective is included and underlined in the national guidelines based on the intention to develop family-focused practices and integrate a family perspective in different services when one family member is ill (27).

Researchers have for decades argued for the widespread adoption of a family-oriented approach across different services providing treatment or support for persons with an SUP, as this has a positive impact on patients, partners, and children (3, 70, 71). Various approaches aiming to focus on the family as a whole have proved to offer relief for family members in general and have a positive impact in motivating persons with an SUP to achieve and maintain abstinence. This is true at both the specialist health care level (72) and the municipal level, whereby general practitioners, social workers, and other relevant service providers are important professionals for the relatives of person with SUP (67, 73).

As documented above, relatives to persons with an SUP experience great challenges in the areas of mental and physical health, as well as in familial and social areas, perhaps particularly when they have a parenting role to fulfill.

In order to inform and include partners to persons with an SUP according to the laws' intention to involve them in treatment (24), or in view of their possible need for information (24, 25), and to be able to identify their specific needs for support (4, 27), it is important to illuminate their life situation specifically. In order to do so, partners' QoL and everyday experiences could be targeted. Understanding their life situation demands that the findings are collated to develop an expanded insight.

3. Thesis aims

The overall aim of this thesis is to provide more knowledge on the QoL and everyday experiences of partners to persons with an (SUP) who share care for children.

The specific aims for Study I (cross-sectional study) were to explore QoL and factors associated with QoL among partners to patients with SUDs who share care for children and to formulate answers to the following research questions: (a) What are the socio-demographic, social/familial, and health variables and perceived QoL in various partner groups? (b) What are the differences in these variables between partner groups? and (c) Which factors are associated with QoL?

The specific aims for Study II (scoping review study) were to examine and map the knowledge of QoL among partners to persons with an SUP, to identify the knowledge gaps regarding their QoL, and to answer the following research questions:

(a) How has QoL been investigated and measured with respect to partners to persons with a SUP? and (b) How do partners report their QoL?

The specific aims for Study III (qualitative study) were to describe the everyday experiences of partners to persons with SUPs and answer the following research question: (a) How do partners of individuals with SUPs describe their everyday experiences, including their parental role?

4. Methods

This thesis follows a partially mixed sequential equal status design, which includes both quantitative and qualitative methods (74), and a triangulation of methods, which encompasses a combination of methods in studying the same phenomenon (75). Partially mixed methods entails that the quantitative and the qualitative parts were conducted before mixing them. Sequential entails that the quantitative and the qualitative studies were performed at different stages, while equal status design refers to the choice of an approach whereby the quantitative and qualitative phases have equal weight (74).

Three different research designs were used in this thesis: Study I adopted a cross-sectional design using a descriptive and inferential statistical analysis methods. Study II adopted a scoping review design using a five-stage framework for conducting scoping reviews (76) and a qualitative content method (77) to analyze the findings. Study III adopted a qualitative, descriptive, and explorative design, with an inductive, thematic analysis inspired by Braun and Clarke (78).

The integration of data from studies I, II, and III took place at the interpretation and reporting phase, in which the findings were written together on a theme-by-theme basis (79). This section is named “discussion of findings across the three studies.”

Table 1: Overview of the studies: design, methods, participants/articles, data collection, and data analysis

Study	Design	Included participants/ articles	Data collection	Period	Analysis
I	Cross-sectional	213 partners to patients in physical, mental, or substance use health units	Questionnaires	2013-2015	Descriptive statistics and hierarchical multivariate regression analysis
II	Scoping review	Nine peer-reviewed articles	Literature search in six databases	2017	Qualitative content analysis
III	Qualitative	10 partners or ex-partners	Qualitative interviews	2014-2015	Qualitative thematic analysis

4.1. Study I, cross-sectional study

4.1.1. Study design

Study I follows a cross-sectional design, using data from a Norwegian multicenter study (hereafter “the larger study”) in which the overall objective was to explore the experience of children with one ill parent, their perceived need for support, and the extent to which they receive support (67).

Study context

Both parents (the patient and the other parent) were included in the larger study to obtain collateral information about the child and report on their situation during illness (67). Thus, the larger study consisted of the child, the patient with the illness, and the other biological parent who was or had been the patient’s partner. The larger study adopted a broad perspective and set out to examine the children’s situations across illness domains within specialist health care services, i.e., in somatic health (severe neurological conditions or cancer), mental health, and treatment services for SUDs. In Study I, the term SUD is therefore used. Participants were recruited in five

Norwegian hospitals. The presently discussed study (I) used a subset of these data to examine the sample of partners ("the other parent" as mentioned above).

4.1.2. Sample

The partners were recruited via patients in the larger study (see above). The patients gave consent to the inclusion of partners, and those partners willing to participate gave written informed consent. The respondents were the current life partners of the patients in the larger study and shared parenthood responsibilities. As Study I focused on the QoL of partners in particular, we excluded from the larger study parents who were separated or divorced. Partners who could not read and write Norwegian were also excluded.

4.1.3. Measures and procedures

A number of demographic and social indicator variables were included, reflecting living conditions, which may be advantageous in examining QoL (61). In this study, age, gender, work/school status, educational level, and income were examined. Occupation and ongoing education, i.e., work/school status, were summarized into an indicator for activity (percentage engaged in work/school), following the example of Barstad (49).

Social and familial variables

The Interpersonal Support Evaluation List (ISEL) was used to measure social support, which includes 12 items on social support in both daily life and crises (80). This instrument is used to measure the perceived availability of four subscales (belonging support, self-esteem support, tangible support, and appraisal support), and the response options range from 1 to 4, with a sum score of 12 to 48 and higher scores indicating higher perceived support. There is no generally accepted cut-off for high versus low perceived social support in ISEL. The mid-point of the scale is 30, and scores above that value indicate a more positive than negative view of the amount of social support available (81). In a US-based general population sample, the mean score was 42.7 (82). The instrument has been used in several countries (83, 84), including Norway, where the Cronbach's alphas ranged from .85 to .88 (85).

The Family Cohesion Subscale (FACES-III) (86, 87) was used to measure family cohesion, with 10 items describing relations among family members and the degree to which family members feel separated from or connected to their family. The responses range from 1 to 5, with a sum score from 10 to 50 and higher scores indicating higher cohesion. A mean score of 39.8 was found in a general population (88), and a score below 40 indicates perceived lack of cohesion. The Norwegian version used in this study has been validated and found to be usable, and the Cronbach's alphas ranged from .82 to .86 for all assessment points (85).

The single question "Do you have any concerns about your child's wellbeing and functioning?" was used to measure partners' level of concern about their children, i.e., worries about their wellbeing and functioning. The question was scaled similarly to the family capacity scale below, with a higher score indicating a greater concern for the child. No normative data for this single item exist, as it has been used only in this study.

A set of questions named "Partner's perceived family capacity" was used to measure whether the partner's care was directed towards the patient's illness at the expense of the children and the partner's own needs. The set of eight questions was constructed for the larger study. The questions were informed by a qualitative study among Norwegian families with SUPs (38). The questions began with the phrase, "Does the condition of the ill parent affect your capacity to . . ." and were completed with phrases covering eight domains, e.g., ". . . do practical housework," ". . . give the children emotional support," ". . . give the children structure," and ". . . participate in social activities with the children." The questions were scored on a four-point scale (0 = not at all, 1 = slightly, 2 = to some degree, 3 = to a larger degree). A high score indicates a high influence of the condition/disease on the capacity of the partner in the family. The Cronbach's alpha was 0.93.

Health variables

The Hopkins Symptom Checklist 10 (SCL-10) was used to measure perceived psychological distress. This is a short-form of the Hopkins Symptom Checklist 90 (89), which has 10 items about anxiety (four items) and depression (six items). Responses were scored from 1 to 4, with the highest score indicating highest distress. A total mean score above 1.85 is considered a pathological score, with a mean score of 1.36 in a general population (90, 91). The SCL-10 assessment is considered to be a good indicator of psychological distress and is validated and considered suitable for use in Norway. The Cronbach's alpha was 0.88 in a Norwegian study (90).

The CAGE Questionnaire Adapted to Include Drugs (CAGE-AID) (92) was used to measure substance use and SUPs among participants. This instrument includes the use of legal and illegal substances, as well as legal substances used in a way other than prescribed. A sum score based on four questions (“yes/no”) was calculated (range 0–4), and a score of 2 or higher indicates an SUP (92). A mean score of 0.9 was found in a hospital population sample of non-SUD patients (93). The national guidelines for the assessment of substance use in Norway recommend CAGE-AID as an assessment tool (94) and the instrument has been used in Norway (95). The Cronbach’s alpha was 0.92 in an American population (96).

Quality of life

The QoL-5 (97) was used to measure QoL. This is a generic, validated instrument covering overall QoL, based on an integrative theory of QoL, and is considered relevant as a disease-nonspecific instrument (97-99). The QoL-5 has been described as useful for measuring the overall QoL in general population samples and across different illness domains (97, 98, 100). It consists of five subjective QoL questions: two on mental and physical health, two on the quality of the relationship with important others (partner and friends), and one regarding existential QoL, i.e., relation to self. Responses are scored on a five-step ordinal scale ranging from very poor to very good QoL and then transferred to a decimal scale from 0.1 to 0.9, where 0.9 is the highest/best score and 0.1 is the lowest/worst (97, 101). The mean scores for health, relationships, and existential QoL were calculated, as was a total QoL score as a mean of the three scores. A mean score of 0.69 was found in a previous survey of the general population (97) and was used as our population reference. The cut-off score for a markedly low QoL has been suggested to be −0.15 below that of the general population (< 0.55) (99). The instrument has been used in a number of studies. It is sensitive to QoL changes and capable of capturing differences in QoL, and has been established as a valid and reliable instrument (97, 99, 102). For Study I, the Cronbach’s alpha was 0.83.

4.1.4. Data collection

The participants were recruited from March 2013 to December 2014. Recruitment and data collection were carried out by a local coordinator and co-workers at each hospital site. Data collection was conducted according to participant choice, usually at their home. The questionnaires required about one hour to complete and the responses were entered on tablets.

4.1.5. Analysis

Descriptive statistics were used to present sample characteristics. Differences between groups were examined using Chi-square for categorical variables. The Kolmogorow-Smirnov test was implemented to ascertain whether continuous variables were normally distributed. As the criteria for a normal distribution were not met, the nonparametric Kruskal-Wallis test was used for the inter-group comparisons. If significant, the findings were followed up with a Mann-Whitney U-test. Before the multiple regression analysis, preliminary bivariate analyses were used to examine factors associated with QoL; factors with a p-value below 0.20 were included in the following sequential procedure following the lax criterion recommended by Altman (103). A stepwise procedure (hierarchical regression) was used to examine the relative influence on QoL of socio-demographic, social/familial, and health variables. In the first step, we included socio-demographic variables (group, gender, education, work/school activity, and income). In the second step, we included social/familial variables (family cohesion, social support, concern for child, and whether the familial capacity was influenced by the illness). In the last step, we added health variables (psychological distress). The dependent variable (QoL) was expected to be skewed towards the higher end of the scale; thus, a bootstrapping procedure (1,000 replications) was used to obtain more robust estimates. The findings are presented as unstandardized beta coefficients with 95% confidence intervals (CIs). The R-squared (R^2) value was used to assess the statistical model's fit. Analyses of variables were considered to be statistically significant at $p < 0.05$. All analyses were performed using IBM SPSS Statistics version 21.

4.1.6. Validity and reliability

Reliability of an instrument refers to its accuracy, stability, and consistency in measuring the construct (104). Validity refers to the degree to which the instrument assesses what it is supposed to assess (104). The validity and reliability of the instruments included in Study I have been accounted for in the description of the instruments (section 4.2.3. Measures and procedures).

As for the new eight-item scale "Partner's perceived family capacity," the factor structure was examined with an exploratory factor analysis using principal axis and an oblique rotation method (promax). Kaiser's eigenvalue-greater-than-one rule was used to determine the number of factors, and items were retained if they had factor loadings > 0.4 (105). The analysis yielded a univariate solution, and only one factor was extracted; all items had factor loadings above 0.57 and the scale explained 67% of the variance. The single question “Do you have any concerns about your child’s wellbeing and functioning?” was scaled similarly to the family capacity scale, but no normative data for this single item exist, as it has been used only in this study.

4.2. Study II, scoping review

4.2.1. Study design

A scoping review was conducted in collaboration with two experienced librarians (J.H. and E.S.), adopting systematic literature search methods. The scoping review is considered a suitable method in areas in which little research exists or when existing studies appear heterogeneous in their findings and conclusions (106, 107). Systematic scoping reviews require formal methods but do not necessarily consider the strength of included studies (76, 107).

The choice of review method was informed by initial searches in Google Scholar, followed by initial searches of existing literature in two databases: EMBASE and PsycINFO. This search indicated that studies investigating QoL among partners to persons with SUPs were limited.

In order to map the broader literature, articles with multidimensional perspectives on QoL were included. We used Levac et al.’s (2010) approach for conducting systematic scoping reviews. A five-stage methodological framework (Arksey & O’Malley, 2005) guided the review.

4.2.2. Sample

The main search was undertaken with the last searches performed on June 23, 2017. The following databases were searched: EMBASE, Medline, PsycINFO, CINAHL, SocINDEX, and CENTRAL. The search strategy included specifications of the context (SUPs), participants (partners), and concept (QoL). Further details are presented in the published scoping review article (108).

Inclusion criteria

Quantitative and qualitative peer-reviewed, original, full-length research articles were included. Research articles identified through a manual search of key references and references known by co-authors were also included. We excluded the following: study protocols and conference papers of which the findings were not published in peer-reviewed journals, articles presented in languages other than English, intervention studies, and empirical articles that were not peer-reviewed.

Participants

The participants in the reviewed studies were current partners to persons with SUPs. They had to be examined exclusively in “pure” partner studies or as a subsample in a total sample of close relatives.

Concept

The key concept that was reviewed was the self-reported QoL, including multidimensional domains, in which at least physical and psychological health domains and social/relational domains occur. Studies with a very narrow focus on wellbeing (e.g., psychological distress only) were excluded.

Context

Substance use in the participants’ partners was characterized or described as problematic, heavy, or severe, or in terms of a medical diagnosis, and as the main condition. The context may or may not include a treatment situation.

4.2.3. Data collection

Search strategy

In performing the search strategy in the six different databases, a total of 3,070 records were identified after removing duplicates. The screening of these records was performed by two authors (BW and BB), who independently screened the titles and abstracts of each record. Agreement was reached regarding the inclusion of 41 records as relevant studies for full-text screening. These were screened individually by four of the authors. Thirty-two were excluded with reasons; the majority because the participants did not represent the relevant group or did not specifically present the findings for the partners to persons with an SUP, or because the focus on wellbeing was considered to diverge too much from the QoL domains. A total of nine articles were finally included in the review. For further details, please see Table 1 and Figure 1 (108).

4.2.4. Analysis

Quality of life issues related to partners to persons with an SUP were analyzed by three authors (BB, BW, and KF) following the steps for qualitative content analysis (77), including three main phases: preparation, organizing, and reporting. One author (BB) extracted additional study characteristics, which were also reviewed by BW and then included in agreement between BB and BW. The study quality (e.g., risks of bias and study strength) was not considered (76). The tables presented in the published article show the systematization and categorization of relevant topics from the findings of the studies included in this review, reflecting the research questions.

To ensure trustworthiness in this study, Arksey and O'Malley's five stages of conducting a scoping review (76) were adapted as described below by Levac et al. (107) and presented in Table 2. More detailed information is presented in the published article (108).

Table 2: The five stages of conducting a scoping review (107)

Stages	**Instruction for each stage**	**Instructions adapted to Study II**
1: Identifying the research question	Clearly defined aspects. Must be broad in nature.	• Discussion meeting in research team to formulate research questions reflecting the aim of the study.
2: Identifying relevant studies	Decision plan for where to search, terms, sources, time span, and language.	• Search strategy discussed in collaboration with research team and two experienced librarians. • Search terms presented in Table 1. • Six databases searched with last search date (June 23, 2017). English peer-reviewed articles included.
3: Study selection	Post-hoc inclusion/exclusion criteria, based on research question.	• Inclusion criteria based on agreement in research team and referred to as "participants, context, and concept." • Study selection presented in Figure 1; PRISMA flow-chart.
4: Charting the data	Developing a data-charting form.	• Developed in Table 2 and Table 3 in the published article.
5: Collating, summarizing, and reporting results	1. Analysis (including both a descriptive numerical summary and a thematic analysis. 2. Reporting the results. 3. Consider the meanings of the results.	• Table 2 contains a descriptive numerical summary in accordance with instructions (overall number of studies included, types of study design, years of publications, and countries where studies were conducted). • QoL issues analyzed by using qualitative content analysis with a deductive approach (77).

4.3. Study III, qualitative study

4.3.1. Study design

A qualitative, descriptive, and explorative design was employed to explore the research question. Such a design was considered appropriate as a method of obtaining a fuller understanding of the everyday experiences of the partners of individuals with an SUP with regard to the SUP of their significant other.

4.3.2. Inclusion criteria

Participants were recruited through the organizations A-Larm (n=4) and Landsforbundet Mot Stoffmisbruk (LMS; in English: National Association against Drug Abuse) (n=1), and through the larger study (n=5). The inclusion criteria were as follows: (1) partners or ex-partners of individuals with an SUP (relating to alcohol and/or drugs), (2) partners who shared parenthood with the SUP-afflicted partner or ex-partner, and (3) partners who had experience in caring for minors during the other parent's SUP.

4.3.3. Interview guide

A semi-structured interview guide with open-ended questions was developed in collaboration with organizations A-Larm and LMS. A-Larm conducts preventive work through information activities and peer support, and cooperates with other organizations and public services. LMS is based upon peer work and several local associations working within their local communities, and represents relatives in a variety of councils and committees. The interview guide contained the following themes:

- How the informants experienced being the relative of someone with an SUP.
- Which roles they perceived to have had as relatives (including parenting role).
- Whether they acquired any useful experiences as relatives.

The informants were asked to give examples of their experiences. Otherwise, the questions were as open as possible.

4.3.4. Data collection

Individual, qualitative interviews were performed with overall themes related to the participants' everyday experiences as partners of persons with an SUP, revolving around their experiences of being the close relative of someone with an SUP, their roles, support needed and received, and possible positive outcomes from their experiences. The same questions were used in all interviews, while the order in which they appeared could vary depending on how the participants addressed the different themes. At the end of each interview, the participants were given opportunity to share any reflections that had not yet been highlighted. The interviews lasted approximately 60 minutes and were performed at the place of the participant's preference (usually the participant's home) during the period from beginning of April to end of September 2014. The interviews were transcribed verbatim.

4.3.5. Sample

All participants met the inclusion criteria. A total of 10 partners participated: six females and four males. Their age ranged from 35 to 66. Two participants shared experiences from the time their partner had an SUP, although they were non-users at the time of the interviews. Both still lived with their partner. The remaining eight participants were ex-partners, of whom four reported the other parent still had an SUP. Seven of the participants were parents to minors at the time of the interviews. One was a student, two were employed (full-time), one was on sick leave, four received full disability pension and one had applied for it, one had a combination of disability pension and employment, and one did not share this information. None of the participants reported on their own SUP.

4.3.6. Analysis

Inspired by Braun and Clarke (78), an inductive, thematic analysis was performed in order to obtain and thematize the participants' everyday experiences, while having a partner with an SUP, including their experiences related to parenting. The interview transcripts were read several times and notes on possible meaning units were taken, with suggestions for coding words (109). The authors met and discussed thoroughly several times, referring to the interview texts when in doubt, in order to develop meaning units, subthemes, and themes.

In the organizing process, we clustered the subthemes in accordance with their content and found preliminary themes. These subthemes and preliminary themes were thoroughly discussed, moving between the interview transcripts and the themes. Several subthemes were rearranged by moving content to another subtheme or changing names. The themes were scrutinized and reorganized several times before we reached the agreement to organize the data into three themes, each with associated subthemes.

4.3.7. Trustworthiness

In Study III, Guba’s four actions to establish trustworthiness were used (110). Credibility was strengthened with the use of open-ended questions and time to invite the participants to share additional reflections in the interviews in order to ensure they were free to use their own words in expressing their views. Transferability was strengthened by a thorough description of the data collection, the informants, and the analyzing process. Interview guides with identical open-ended questions for all informants were used to ensure dependability. Confirmability was sought by presenting and discussing preconceived notions of data in the research team and comparing our findings with relevant, peer-reviewed studies. Dependability was strengthened by using the same semi-structured interview guide in all interviews. To ensure the trustworthiness of the findings (110), citations from the participants’ responses are included in the presentation of the findings.

4.4. Mixed methods

In this thesis, the quantitative and qualitative elements were conducted before mixing (partially mixed), and the parts were performed at different stages (sequential), placing equal weight on the different designs. The cross-sectional study (I) provided a basis for understanding partners’ QoL across three patient diagnosis groups. Further, the present knowledge base of QoL in the particular partner group (partners of persons with an SUP) was investigated in the scoping review (II). Lastly, the understanding of how partners of persons with an SUP experience their everyday life was deepened through the qualitative study (III).

Finally, the findings from the three studies were scrutinized, assembled, and reported to arrive at an expanded understanding of the findings (79). According to Leech and Onwuegbuzie (74), in a partially mixed sequential equal status design, the findings from studies with different designs can be presented and discussed separately. In order to obtain an expanded understanding of the findings, the mixing took place in the stage following the discussion sections for each of the studies (I, II, and III). The mixing was compiled towards obtaining a discussion of the main findings across the three studies presented in this thesis.

4.5. Ethics

For studies I and III, all procedures performed were in accordance with the ethical standards of the national research committee, as well as with the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards. The studies were approved by the Regional Committee for Medical Research Ethics (REK; approval no. 2012/1176 A) and by the data protection officer for the participating hospitals.

Data concerning Study I were recorded as disidentified data on a server, and all data transfer was made in the form of encrypted files. The forms contained a code number that linked the informant to a list with the informants' identity at the individual hospital. This list was properly locked at the hospital and thus separated from the data from the questionnaires. Only the local project manager and the interviewers had access to it.

The interviews for Study III were stored on an encrypted memory stick, data were made anonymous in the transcription and analysis processes, and pseudonyms were adopted in the citations used in the submitted article and this thesis. The signed informed consents from studies I and III were kept locked at the hospital, according to the hospital's routines for storing sensitive research data.

In order to protect the study participants, another overall ethical principle is the respect for dignity and the right to self-determination, which encompasses participants' right to make informed, voluntary decisions about study participation. According to this principle, both the purpose of the study and the execution must be revealed (111). Signed, informed consent was obtained from all individual participants included in studies I and III.

The questionnaires used in Study I may have been disturbing to the participants, as they involved themes such as psychological distress, worry for children, and other topics related to being a partner to and sharing parenting with a person with an SUD, mental illness, or severe physical illness. A procedure protocol concerning these themes was followed. The participants were informed about this, as well as about the interviewer's acknowledgement of the need to take breaks during the process of filling out the questionnaire and even the possibility to decline participation without any negative consequences. When the interviewer considered it necessary, he or she called the participants back to ensure they were ok. The procedure protocol also included performing procedures for referrals to further health services if the participants expressed such a need.

The qualitative interviews conducted in Study III also involved themes that may have been perceived as emotional or sensitive by the participants. The interviewer (BB) informed each participant that reactions might occur and that they were free to ask or stop if any of the questions seemed difficult. Their self-determination was emphasized by informing them of their choice regarding the extent to which they wanted to elaborate on the answers. None of the partners wished to end the interviews, but instead insisted on describing their experiences, with many of them indicating this was the first time anyone had ever asked them. One participant expressed a need for further contact with a mutual support group, and the interviewer contributed to establishing contact with such a group before the participant left. At the end of the interviews, the participants were asked if any questions had been too sensitive or emotionally difficult, which none of them stated was the case. Despite the fact that some of the participants clearly appeared to be emotionally affected, they underlined their gratitude for being asked to describe their experiences.

5. Main findings

The findings from the cross-sectional study (I), the scoping review study (II), and the qualitative study (III) are presented successively in the sections below, followed by a bulleted summary of the findings from the three studies.

5.1. Cross-sectional study (I)

5.1.1. Perceived socio-demographic, social/familial, and health variables and perceived QoL, and differences between partner groups

The total sample consisted of 213 partners: 116 in the somatic illness domain, 72 in the mental illness domain, and 25 in the SUD domain (please see Table 1 in the published article (112)]). We found significant differences regarding socio-demographic variables across groups. The proportion of women was significantly higher among partners in the SUD group. Partners in this group also reported having a significantly lower income and lower education level, and less work/school activity, compared to the other two groups.

The mean scores on instruments covering social and familial variables were in line with the normative population (82, 88). The participants had little worry for the child/children and reported that the perceived family capacity was only modestly affected by their partner's illness. There were no significant differences across groups regarding any of these variables. In terms of the health variables, only 7 (3%) scored above the cut-off for severe SUPs (CAGE-AID), with a slightly higher proportion of problematic substance use in the SUD partner group. Regarding perceived psychological distress (SCL-10), the mean score was below the pathological cut-off for all three groups. No differences in perceived psychological distress (SCL-10) emerged among the three illness domain groups. The QoL scores for the sample as a whole (0.71, SD 0.14) were similar to those of the normative population (99), with no significant differences among groups (please see Table 1 in the published article (112)]). A small proportion of the sample (13%) reported a markedly low QoL (< 0.55).

5.1.2. Variables associated with QoL

In bivariate analyses, age and substance use (CAGE-AID) had p-values above the recommended lax criterion ($p > 0.2$); thus, they were excluded from further analysis and the following model. The first step of the hierarchical regression (socio-demographic variables) (please see Table 2 in the published article (112)]) showed that income and work/school activity were significantly associated with QoL. This model explained 6% (R^2) of the variance. In the second step of the hierarchical regression, we added social/familial variables; family cohesion (FACES-III), perceived social support (ISEL), and perceived worry/concern about the child/children were significantly associated with QoL (Table 2 in the published article (112)]). This model explained 33% (R^2) of the variance in QoL. The final model included health variables, and only two variables were significantly associated with QoL: perceived family cohesion and psychological distress. Perceived family cohesion was positively associated with QoL, while psychological distress (SCL-10) was a negative predictor (beta = −0.16; 95% CI = −0.20/−0.13, $p < 0.001$; Table 2 in the published article (112)]). The final model explained 56% (R^2) of the variance in QoL, as shown in Table 2 (112).

5.2. Scoping review (II)

The findings refer to stage 5 (collating, summarizing, and reporting the results) from Arksey and O'Malley's framework for conducting a scoping review (76). The review findings are presented according to the review questions. Table 3 in the published article (108) reports the general information and major findings of the reviewed publications.

5.2.1. How the QoL of partners to persons with an SUP was investigated and measured

Eight of the nine included studies had quantitative designs (21, 113-119), one had a mixed methods design (56), and no qualitative studies were found. Three studies were conducted exclusively among partners (21, 113, 114), whereas the others included various subgroups of relatives to persons with an SUP, including partners. A majority of the participants in all studies were women. In reporting on socio-demographic details, three of the nine included studies reported that more than half of the partners were parents to minors living in the household (21, 113, 116).

The studies used established and generic QoL instruments based on different conceptual and theoretical perspectives on QoL. Five of the studies used established instruments covering health-related QoL (21, 115, 116, 118, 119). Two of the remaining studies used different QoL instruments covering a range of QoL dimensions, including at least the health, social, and relational domains (114, 117). The last study included a single question asking the participants to rate their perceived overall QoL (56) and a qualitative part with questions about health and wellbeing, which was intended to cover QoL. These are presented in Table 3 in the published article (108).

5.2.2. How partners reported their QoL

Five of the included studies reported the QoL exclusively among partners (21, 113, 114, 116, 118). A majority of the studies found lower QoL among partners to persons with an SUP than in the general population or controls, with substance use by the person with an SUP having the greatest impact on QoL of all evaluated factors (21, 56, 115-118). Two studies reported that gender was associated with QoL. One of these studies (113) found that male partners reported a lower QoL than female partners and that the male partners' lower QoL was associated with poor relationships with their children and poor social support skills. The other study did not differentiate between subgroups, but found that being a female relative with poor education and low income was associated with poor QoL (115). The further findings varied to a large extent.

5.3. Qualitative study (III)

Ten partners who shared parenting with persons with SUP participated in Study III: six were women and four were men, with ages ranging from 35 to 66 years. Two participants still lived with their respective partners. The remaining eight participants were ex-partners, of whom four reported their co-parent still had SUP. Seven of the participants were parents to minors at the time of the interviews, whereas the children of the other three were adults. None of the participants reported having SUP themselves.

The findings show that sharing life with a partner with an SUP meant that their partner's problems affected every part of their lives. Through our analysis, three main themes emerged: "relational strains," "stigma, shame, and lack of support," and "searching for hope and meaning." These themes are presented in Table 1 in the submitted article. The participants emphasized they often felt unsafe, and that the unpredictability of the situation was burdensome but difficult to escape. To be close to someone with an SUP meant being dependent on their ups and downs. The overall theme was thus named as "Being stuck on an unsafe and unpredictable rollercoaster."

5.3.1. Relational strains

This theme revolves around the participants' everyday experiences of strains induced by their relationship with a partner with an SUP.

The participants' familial roles were altered and they typically felt increasingly alone and lonely in bearing the overall family responsibilities. They sometimes also had to protect their children from emotional or physical dangers caused by the other parent. The participants described that their own wellbeing was closely related to the consequences of the SUP: they could feel better when the substance use decreased—though not without fear of relapse—and worse when it increased.

The participants described periodically overwhelming dilemmas, particularly regarding how to balance children's need for understanding the situation whilst protecting them from knowing too much. Participants who were ex-partners experienced additional strains related to visitations between the children and the parent with an SUP.

A huge strain to the participants regarded the negative consequences of the SUP on the family's safety and security. This included experiences of being manipulated, harassed, and exposed to conflicts, threats and violence from their partner, and the unpredictability of the substance use.

The totality of strains was described as being linked to a vulnerable health status, as manifested in bodily stresses and pains, weight loss, and various emotional or mental difficulties such as sleep disturbances, concentration problems, depression, and anxiety.

5.3.2. Stigma, shame, and lack of support

This theme describes how the participants experienced the SUP affected them with regard to the following subthemes: impacts on oneself, children, and social life, and lack of support.

The stigma and shame affected how the participants viewed themselves, their children, and their (lack of) social life. A common fear was that others would reveal the SUP and, if this occurred, how the stigma would affect the family members. The shame or guilt they felt was threefold: of the substance misuse and their partner's conduct, of not being able to help/that the SUP was indeed their fault, and for not leaving when the SUP affected the children.

The lack of support was mostly described in relation to the health services provided to both their partners and themselves. Lack of support from family and friends was also themed. However, several of the participants mentioned that peer support groups had been of great support to them.

5.3.3. Searching for hope and meaning

This theme describes the participants' journey regarding the subthemes: from hope of change to loss of hope, re-establishing hope, gaining new meaning, and still feeling vulnerable.

The participants described the years of trying without bringing about any changes as a process of "ups and downs," with a never-ending fear of relapse. They slowly lost hope for change and reached "rock bottom" or a point of no return.

Many of the participants described in retrospect that they were only able to re-establish hope, find meaning, and learn from their experiences after reaching this point of no return. It was essential to take distance to the SUP-afflicted person, whether their partner recovered or they ended the relationship.

Although having reached a point in life in which they were able to reflect back on a very challenging period, the participants could still feel weak and vulnerable, even though they seemed strong on the outside. Even when having ended the relationship with their partner, their worries and strains were sustained, as they shared parenthood. It still took a lot of effort to ensure the children were safe and felt well, especially when the other parent still used substances.

5.4. Summary of the findings

5.4.1. Cross-sectional study (I)

- The mean QoL score was similar to that of the general population sample, but 13% of the sample had a markedly low QoL.
- Partners in the SUD group experienced worse socio-demographic conditions in terms of occupation and income compared to the other two groups, but the QoL did not differ significantly between the three groups.
- In the regression model, perceived family cohesion was positively associated with QoL, while psychological distress (symptom checklist-10) was negatively related to it. The model explained 56% of the variance in QoL.

5.4.2. Scoping review study (II)

- Eight of the nine included studies had quantitative designs, one had a mixed methods design, and no qualitative studies were found. Three studies were conducted exclusively among partners to persons with an SUP, whereas the others included various subgroups. A majority of participants were women, and no study was conducted exclusively among men. Three of the studies reported on whether there were minors in the partners' household, which was the case for more than half of the partners in these studies.

- The studies used established and generic QoL instruments based on different conceptual and theoretical perspectives on QoL.
- A majority of the studies found a lower QoL among partners than in the general population, with substance use by the person with an SUP having the most impact on QoL of all evaluated factors. Two studies reported that gender was associated with QoL, with poor QoL being associated with being a male partner and vice versa for female partners.

5.4.3. Qualitative study (III)

- Sharing life and parenthood with a partner with SUPs affected every part of the participants' lives and entailed their dependency on their partner's ups and downs.
- The overall theme "Being stuck on an unsafe and unpredictable rollercoaster" is explored through three main themes: "relational strains," "stigma, shame, and lack of support," and "searching for hope and meaning."
- As a result of the negative impact of their circumstances on their everyday lives, these individuals need support in order to handle the challenges they face but find it difficult to ask for help for fear of stigma.
- Peer support groups seem essential in enabling them to find ways out of their situation.

6. Discussion

6.1. Discussion of the findings

In this section, the findings of the three studies are first discussed separately, followed by a discussion of the findings across these studies.

6.1.1. Study I (cross-sectional study)

The normality of the QoL scores in this population was unexpected in light of the known strain of having an ill partner (120-123). Previous studies among partners to ill patients show that if the patient received treatment, this had a positive impact on the partner's QoL (120, 124, 125). Our participants were recruited during a treatment period for the ill parent, which may partly explain the unexpectedly high QoL in our sample. However, in the long run, treatment does not necessarily lead to a better QoL in the partner unless the patient has a remission (21, 114, 125). Nonetheless, 13% of the participants reported a markedly low QoL, indicating that a relatively small proportion of the sample struggled with their life situation.

As for several socio-demographic conditions, the partners in the SUD group were worse off; for example, they were less likely to be occupied with work or school and had a poorer educational level and lower income than the other two groups. These findings were however not reflected in a poorer QoL at the group level. In general, poorer socio-demographic conditions seem to affect QoL negatively (126); however, the subjective experience of such conditions affects QoL more than the "objective" differences (127). Thus, in line with previous research (128, 129), the overall QoL is more than a measurement of objective demographic conditions: it reflects how the individual relates to these conditions. An alternative explanation may be that when the patient receives treatment, the partner in the SUD group experiences a relatively greater relief from worries and burdens, and perhaps perceives temporal relief from their worries (114) that might have influenced on their self-assessment. Another explanation might be that the sample probably consisted of those with the most stable life situation and a low conflict level (Ruud et al. 2015).

Family cohesion was retained as a significant factor associated with QoL in the final regression model. This outcome has been examined in previous studies among partners of patients with illness and accentuates the importance of perceived proximity and cohesion in close relations in view of retaining QoL (20, 114, 122). The experience of instability and insecurity that partners of ill patients report may affect their perceived family cohesion and also impact their QoL (22, 122).

Psychological distress (SCL-10) was the strongest variable explaining variations in QoL. A one-point gain (higher psychological distress) resulted in a 0.16 lower QoL-5 score in the final adjusted model, suggesting a substantial influence in applying the clinical interpretation of the scale (98). The model's fit was also considerably strengthened, and the explained variance in QoL increased from 33% to 56% with the inclusion of this health variable. Feelings of hopelessness, worry, stress, and depression have been observed in partners of somatic or mentally ill patients (121, 123), as has anxiety in relatives of SUD patients (21, 117). Such negative emotions may underlie the psychological distress reported in the present study, which in turn strongly predicted poorer QoL. High psychological distress likely makes individuals less able to cope with a difficult situation arising when a close relative suffers from an illness. Other studies also report strong correlations between psychological distress and poor QoL (20, 21, 120, 124, 130), affirming the findings of our final model. However, with the present design, we cannot discern whether the reported psychological distress existed before the illness or comprises a reaction to having an illness in the family.

6.1.2. Study II (scoping review study)

The studies included in this scoping review exploring the QoL experiences of partners to persons with SUPs originated in a wide range of countries, and the majority were conducted after 2010, which indicates an increased interest in research focusing on both QoL and this group of partners. Only one study with a mixed methods design (56) was included, while no qualitative studies that matched our inclusion criteria were found. The majority of the studies used established and generic instruments in examining QoL. However, these instruments are based on different concepts and theoretical perspectives of QoL; therefore, findings cannot be consistently compared across studies. Many studies also utilized different comparison groups (e.g., the general population, people who had no person with an SUP in their life, controls, patients vs. partners and vs. parents, etc.), which shows a heterogeneity among studies.

As for the instruments used to measure QoL, two of the studies (115, 118) that used the EQ-5D (131), a QoL instrument solely covering health domains, added the Personal Wellbeing Index (PWI) (132) with broader domains. Three other studies (21, 116, 119), each using SF-12 (133), EQ-5D (131), and SF-6D (134), did not include other instruments to add additional domains other than health in reporting on QoL. As health-related QoL measures often refer to a patient's illness and treatment (135), and tend to be more "objective" as they target specific functioning levels, they may have been considered suitable in examining health-related QoL in persons with SUPs. The question remains whether this reflects the QoL domains that are most important to family members or relatives in general or to partners specifically; these persons may experience a difficult life situation but are not necessarily ill. The remaining four quantitative studies (9, 113, 114, 117) used instruments covering a wider range of QoL domains, in addition to health. This included at least social and/or relational domains and in some cases even existential or environmental domains. In conclusion, though all the instruments covered the health dimension, only half of the studies made use of instruments that embrace broader dimensions of QoL, including at least social and relational domains. Therefore, the findings are heterogeneous because researchers do not consistently use the same measures. Many studies only include particular dimensions of QoL rather than adopt a comprehensive concept of QoL. The mixed methods study (56), which includes an overall question about QoL, introduces a broader perspective on QoL by including a single qualitative question about the participant’s wellbeing in various areas. This qualitative information can provide further contextual information and explanation for quantitative findings, and may be useful to include in future research on QoL.

For future research on partners to persons with SUPs, QoL measures that capture the broader dimensions of QoL are recommended. In addition, generic instruments that provide the possibility of cross-population comparisons would be useful. It also appears that multidimensional QoL forms better capture variations in the life situation of these partners and provide a more holistic understanding of the impact of their overall life situation on their QoL. Of the instruments included in the studies in this review, only WHOQOL-BREF includes social, relational, and existential domains in addition to physical and mental health. To capture more domains than those covered by the highly health-specific instruments (e.g., EQ-5D, SF-6D, and SF-12), these instruments can be used together with PWI, which also includes social, relational, and existential dimensions.

Only three of the included studies focused on partners exclusively, while two of the studies including partners as a subgroup reported on their QoL. The remaining studies did not differentiate between subgroups in presenting their QoL findings but rather presented them as applicable to the entire sample. Thus, more research is needed focusing on partners exclusively. In the case of socio-demographic variables, the average age of partners is relatively low (42 years), which may reflect the fact that three of the nine reviewed studies described over half of the participants as caring for minors. Parenting was however not themed specifically, which indicates a knowledge gap. On average, women comprised over three-fourths of the participants. This is in line with other research conducted among partners to persons with an SUP, in which the proportion of women is often higher (22, 39, 136). While the findings of Dawson et al. (21) represent female partners only and the rest of the studies report a majority of female partners, no studies were found focusing exclusively on male partners. Therefore, there is a knowledge gap regarding the QoL of male partners, which is critical especially as male partners report very poor QoL (113), indicating that further research on male partners' QoL is needed.

A key finding of this research is that the majority of the studies found that substance use by the person with an SUP was the factor that was most strongly related to poor QoL among the participants, including partners (21, 114, 116, 118). An association was found between severity of SUPs and poorer QoL among partners (115, 116, 118). The majority of studies also report that the participants, including partners, described a lower QoL than the general population. These findings indicate that substance use itself has a great impact on the partners' QoL. One study among female partners to persons with an SUP found that the participants' QoL was more strongly affected by their partner's SUP than the participants' own substance use (21). In addition, several studies show that partners had an equally poor QoL as that of people with SUPs, which indicates a very stressful life situation. Although they are not by definition ill, long-term and serious SUPs have a major impact on partners' QoL. In future research, using a broad measure of QoL that includes at least health, social, and relational dimensions, rather than exclusively health-specific QoL measures, could be more suitable for capturing partners' life situations.

The findings describing associations with QoL varied greatly. In addition to the impact of SUPs on QoL, several specific findings need to be discussed and addressed with respect to partners. Firstly, there were variations in the degree to which the studies report on partners' possible own SUP, and if they did, the findings also differed regarding whether the participants had an SUP and how this might affect their QoL.

Hence, it cannot be determined how the partners' own substance use and their partners' SUP respectively impact partners' QoL. This finding represents a gap which needs to be further examined in future research. Secondly, the fact that three of the studies (21, 113, 116) report on whether the partners had minors living in the household must be considered in presenting this variable's associations with QoL. This is especially important when poor QoL was found to be associated with being male and poor parent-child relations (113). Several studies show that the parent-child relationship is disrupted due to parents' SUPs (16, 38, 137). The partners' poor QoL may influence their capacity to fulfill the parenting role. Taken together, these findings underline the importance of dedicating attention to partners who also have a parenting role. Possible negative outcomes for partners are relevant not only in order to tailor support for their own sake, but also to enhance parenting and prevent negative outcomes for the children. Conversely, better parenting abilities may reinforce parents' overall situation (138).

As for partners' positive associations with QoL, one study conducted in 1997 found that positive behavior towards the SUP-afflicted partner was associated to some degree with the partners' QoL (114). Though these are also important findings to address clinically, a minority of studies seem to examine other factors associated with QoL in partners, both positive and negative. Studies reporting on partners' positive associations with QoL appear to be limited, and there is a knowledge gap in this area. Studies investigating and exploring QoL qualitatively and quantitatively in partners to persons with an SUP are also needed.

6.1.3. Study III (qualitative study)

Overall, the findings show that the experience of partners of individuals with an SUP was that their everyday life depended on the state of their partner's SUP. Their own needs, such as health care, social life, and safety, were less attended to. It was challenging to be the sole adult taking on the overall familial responsibilities, particularly regarding parenting responsibilities. Hopelessness emerged as the participants experienced repeated relapses and witnessed conduct that induced distrust in their partner. These findings are in line with the experiences described by relatives in general of individuals with an SUP; strategies by which to deal with the situation may include restraining oneself, providing uncritical support, or resigning oneself to the situation, and thus accommodating the person's SUP (11), as well as experiencing worries, anxiety, depression (36, 139), uncertainty (136), social and/or relational struggles, and hopelessness (11, 39). Studies of relatives' QoL when a family member suffers from an SUP found that a poor relationship with the SUP-afflicted family member is tied to poor health in the relative, which often includes giving up social activities (9, 30).

As with SUP in our study, addiction in a partner has previously been shown to become the "center of gravity" in families with a member with gambling problems (140). This indicates that addiction issues are overwhelming and consuming for family members. Our findings show that the participants' lack of safety and security was linked to relational strains with their SUP-afflicted partner, such as exposure to manipulation, aggression, and violence, sometimes witnessed by their children. Chermack, Murray (141) observed high levels of psychological (77%) and physical aggression (54%), and violence (33%) in situations involving a partner with SUPs. Protecting children from such experiences is crucial.

Courtesy stigma (142) or stigma by association (143) means that the family members, for instance, of people with an SUP are exposed to stigma, as well as to self-stigma (144). This might lead to families concealing the problem in order to avoid social exclusion, in line with our study's findings. The importance of social support in such situations is emphasized in the literature (30, 33, 39). Relatives' experiences of barriers to acquiring such support should be acknowledged (11).

This study shows that partners' need to protect themselves, their children, and their partner induced several dilemmas. Such dilemmas have previously been shown to put further strain on relatives (145), including the relatives of individuals with an SUP (11).

In the present study, participants' approaches to managing these dilemmas included avoiding social settings, keeping quiet to avoid family conflict, threats, and violence, and finding ways to safeguard their children. Osborne and Berger (146) found that parental substance abuse puts children at risk for negative health and behavioral outcomes. Prioritizing the children could be at the expense of the partner with an SUP, which illustrates one dilemma faced by participants. One way out could be to keep one's distance from the other parent. Research indicates that partners of individuals with an SUP may keep their distance in order to fulfill their parental role on a daily basis (33, 37-39). As in the case of the dilemmas reported in our study, other studies show that while safeguarding their children, partners are also very supportive of their SUP-afflicted family member and try to keep household matters in order, such as housekeeping, finances, and other family-related tasks (33, 37).

In trying to orient themselves towards the future, all of the participants described reaching a "point of no return," which implies their recognition that they cannot change the situation, either by trying to make their partner stop using substances or by staying in the situation. The impact on several areas of relatives' lives caused by their efforts to induce change with limited success has also been described in other studies (11, 36).

At this point of no return, the participants had reached "rock bottom," which for the majority meant they had to distance themselves from the person with an SUP. Some experienced this as a "turning point," which has been described as an opportunity to overcome disadvantages in life (147). Although our study shows that participants described a turning point based on reaching “rock bottom,” this did not happen without the prior process of hope turning into hopelessness. Reaching an awareness of necessary change has been described as a “catalyst for change,” often triggered by one or more critical life events (33).

Many of the participants experienced a change in their situation after acquiring some distance from the SUP, either through their partner’s recovery, or by leaving him or her. Many of the participants reported in retrospect that this process of change led them to find new meaning in life. Peer support groups were highlighted as essential in this regard. Naylor and Lee (33) found that partners must acquire an increased capacity for self-reflection in order to foster a better focus on themselves. Our study shows that the acquisition of some distance from the SUP-afflicted person appeared essential in improving participants’ capacity for self-reflection.

Although most of the participants described experiencing improvement in their everyday life after having distanced themselves in one way or another from the SUP, they still felt vulnerable. This finding indicates it would take a long time for them to heal from their experiences as relatives. Their ongoing worries about relapse were strongly related to concerns for their children and concerns that such an event would again imply strains, stresses, burdens, and a lack of safety and security, both for their children and themselves. This seems to support the fact that relatives’ descriptions of their greatest worries for the future relate to issues concerning their children, as well as the view that a degree of withdrawal (from SUP) and gaining one’s independence remain important in coping with the situation (30). Withdrawal from SUP might be in form of the person recovering, or that the partner ends the relationship with him or her.

6.2. Discussion of findings across the three studies

In sum, partners’ life situation when the other partner has an SUP, have according to studies II and study III a negative impact on both their QoL and their everyday experiences, as the SUP affected every part of their lives.

A discussion of the main findings across the three studies I, II, and III will be presented in the following. The main points being discussed are: Partners’ perceived QoL, and the SUP’s impact on their QoL; Measuring partners’ QoL; Knowledge gaps concerning these partners’ QoL; partners’ everyday experiences, including parenting. The discussed themes will be summarized at the end of this section.

6.2.1. Partners' perceived QoL, and the impact on their QoL

According to *Study I*, partners to patients referred to SUD treatment did not report lower QoL than a general population and may experience a stable situation in the absence of SUP in their partner. These findings should however be seen in conjunction with the overall findings in Study II, which show that partners reported a significant lower QoL than a general population, whereby the lower QoL was first and foremost associated with their partner's SUP.

As for further associations with QoL, Study I shows that low QoL was significantly associated with psychological distress. Such an association is supported by the findings in one of the studies included in the scoping review (II). Though other studies conducted among partners to persons with other illnesses also report strong correlations between psychological distress and poor QoL (20, 120, 130, 148), we cannot discern whether the reported psychological distress in Study I existed before their partner's SUP occurred or rather comprised a reaction to experiencing the SUP. The findings in Study III show however that the totality of strains was described as manifested in various physical and emotional or mental difficulties such as bodily stresses and pains, weight loss, and various emotional or mental difficulties such as sleep disturbances, concentration problems, depression, and anxiety.

Good QoL on the other hand, was associated in Study I with family cohesion. This may indicate a sample experiencing stability in life to some degree, as the SUP patients probably experienced abstinence as a result of treatment at the time of the study. The studies included in Study II report to a smaller degree on positive associations with QoL, although one of the studies reports that the participants' satisfaction with a support group was associated with better overall QoL (56). The findings in Study III also show that participants who had found peer support groups reported this made a huge difference to them, in particular with regard to no longer being alone and lonely.

6.2.2. Measuring partners' QoL

As for measures used to investigate QoL, Study II shows that very few studies have been conducted among partners exclusively, in which case QoL has often been measured using questionnaires adapted to relatives to persons with an SUP in general, or to persons or patients admitted to treatment and diagnosed with SUDs.

Study I suggests however that short, generic, and multidimensional QoL measures can be useful in capturing which families struggle most, but the context of whether an SUP is present in their partner should be taken into consideration in both clinical settings and research studies.

6.2.3. Knowledge gaps concerning partners' QoL

No qualitative study was found focusing on partners specifically. Further, the findings presented in the scoping review were heterogeneous, both in terms of the associations they include with QoL other than SUP and because they used different questionnaires to measure different kinds of outcomes. Three studies included in Study II report on whether partners had "children living in the household" in presenting their socio-demographic findings, which was the case for more than half of the participants in these studies. Despite these facts, the parenting aspect is discussed to a limited extent in the articles included in the review.

6.2.4. Everyday experiences

As for study III, the overall theme was "Being stuck in an unsafe and unpredictable rollercoaster." Further, three main themes emerged: "relational strains," "stigma, shame, and lack of support," and "searching for hope and meaning." Close interconnections between these themes were found and should be taken into consideration. The participants underlined they often felt unsafe and that the unpredictability in the situation was burdensome and difficult to escape. Their familial roles were altered; they typically felt increasingly alone and lonely while taking on the overall family responsibilities.

To be close to someone with an SUP meant being dependent on their ups and downs. Although most participants described a better everyday life after having distanced themselves in one way or another from the SUP; either by leaving the person with an SUP, or because the person had managed to recover from the SUP, they still felt vulnerable. This indicates their experiences as relatives take a long time to heal.

6.2.5. Parenting

The relational strains and unpredictability particularly affected their parenting role: instead of having a partner as a co-parent, they sometimes had to protect their children from emotional or physical danger imposed by the other parent. Their ongoing worry for relapse was strongly related to concerns for their children and the prospect this would again imply strains, stresses and burdens, and a lack of safety and security, both for the children and themselves. This seems to support descriptions indicating that relatives' greatest worries for the future are issues concerning children, while the degree of withdrawal (from the person with an SUP) and gaining independence are still important in coping with the situation (30).

6.2.6. Summary

Study III does provide important information about the challenges the partners encounter and their need for support, especially when they have a parental role to fulfill. The fact that their partner receives treatment may have a positive impact on their QoL (Study I), and support from mutual peer groups may have a positive impact on both their QoL (Study II) and their everyday experiences (Study III). Nevertheless, when partners are provided with time for reflection during an interview (Study III) they elaborate extensively on various areas of a challenging situation, including parenting and an ongoing concern for children. Despite a better perceived QoL when their partner with SUP is in treatment or after taking distance to that person, they might need support for their own sake. Those partners who still care for minors might also need support in order to handle the challenges they face concerning parenting when the other parent has an SUP.

6.3. Methodological considerations

Though the mixed methods research represents different typologies of mixing, the final product should contribute more than the sum of the study’s different quantitative and qualitative parts. A genuine integration of such a perspective occurs when analysis and interpretation are performed in such a way that the qualitative and quantitative parts mutually illuminate each other (149). In this thesis, the instrument used to measure QoL in Study I was chosen in view of capturing as broad a perspective as possible using a short, generic questionnaire containing health, social, relational, and existential QoL dimensions. Differences in contexts and samples may also be important in comparing results from different studies and methods. The positive QoL findings may be related to the fact that the partners who participated in Study I were recruited while the other partner was in treatment. The patient with SUPs had to consent to the partner's participation, and the possibility that the partners in Study I experience less SUPs and minor conflicts should be taken into consideration (67). Other research have found that when the family member with SUP received treatment over time (125), this had a significant positive impact on the relatives’ QoL. We have however no information about the length of treatment concerning the partner with SUP in Study I. In addition, there is no information about their QoL before the onset of the partner’s SUD or before the partner received treatment. Finally, it could be questioned whether the questionnaire is sufficiently sensitive to capture changes in this population. Gill & Feinstein (64) conclude in their review that when investigating QoL, supplemental items should be allowed that participants could add to describe important factors not included in the instrument.

The scoping review (Study II) did not consider the study strength of the included studies, which may have caused certain limitations, although the overall aim of such a review is to map the range of literature in a given research field, and not to consider the quality of the included studies. The fact that individuals’ SUPs have a very negative impact on their partners’ QoL nevertheless reinforced the assumption that the sample in Study I may not have experienced the present SUP as their partners were enrolled in treatment. The heterogeneous findings in the review, especially concerning the instruments used in the included studies, were very different and based on different theoretical frameworks. Though a scoping review does not consider study quality (contrary to a systematic review), these findings represent a knowledge gap concerning partners’ QoL. This makes it difficult to determine whether a short, non-disease specific generic and multidimensional questionnaire can capture the QoL of partners to persons with an SUP.

As for Study III, the partners describe many challenges concerning their relation to the person with an SUP (i.e., when the SUP-afflicted parent has had a relapse), which they describe as obstacles to their safety, security, and even health. These contextual concerns may not be captured even by using a generic and multidimensional QoL questionnaire, which also underlines the importance of investigating daily experiences qualitatively in this particular group.

Several further limitations must be kept in mind. As in Study I, the sample may be biased in Study III, in which the participants were recruited in a period in which they took “distance” to a presumably very difficult situation with their partner’s SUP: half of the participants were recruited from NGOs and the other half when their partner or ex-partner was enrolled in treatment. Partners of patients with an ongoing SUP may thereby not be present in either Study I or Study III. On the other hand, the experiences from the partners’ descriptions in Study III in retrospect provide extended information on their former relationship with a partner with an SUP. Further, though this thesis uses various methods to illuminate the investigated phenomena, the findings do not necessarily provide exhaustive answers to the partners' life situation.

Despite these limitations, the mixing of methods in this thesis has nevertheless been performed in a way that strives for the qualitative and quantitative parts to mutually illuminate each other. The investigation of the life situation of partners to persons with an SUP, with a specific focus on the phenomena QoL and everyday life, has provided a more comprehensive understanding of this research problem than a quantitative or qualitative approach alone can provide.

6.3.1. Reliability and validity of Study I

The strengths of this study include an acceptable sample size and the inclusion of groups of respondents who have not been compared before, as previous studies focus on separate domains. The instruments used in this study have been considered to be valid and reliable, with high Cronbach's alphas for all the instruments.

However, several limitations must be kept in mind. The sample size per group may not be large enough for detecting statistically significant differences between them. Furthermore, the participants were recruited while the ill parent was in treatment, which may limit the representativeness of the findings. Although socio-demographic variables differed among the groups, the findings indicate that no respondents were recruited with extreme economic or social disturbances in their lives. One possible question is whether those who did not participate experienced more disturbances than those who did (121). The attrition analysis shows there was a lower inclusion rate in the mental health and SUD illness domain, indicating that our findings may be positively biased in these two illness domains. Further attrition analysis was however not possible because administrative data on non-inclusion were insufficiently registered. The limited sample size per group also prevented us from examining whether there were different associations between the independent variables and QoL across groups, i.e., with separate regression analyses for each group. In spite of the limitations, the findings provide important information about the obstacles and facilitators of QoL among partners, which may be informative for further research and interventions.

6.3.2. Trustworthiness of studies II and III

Scoping review (Study II)

The main strength of the scoping review is its comprehensive database search without a date limit. The search was conducted with comprehensive search terms, which identified a large number of studies. This strength is largely due to the close collaboration during the search with two highly experienced academic librarians from different disciplines. The titles and abstracts were screened thoroughly and systematically by two authors. Full-text studies were further screened by four authors, after which reference lists were drafted and discussion meetings were held, which also assured against a loss of relevant studies**.** However, studies in languages other than English were not included, which may have caused a number of relevant records to be missed, for example studies written in a Scandinavian language and thereby conducted in a similar and comparable population. Though the search was performed in six databases, this number is not exhaustive. The selected databases and the performed search were however advised by experienced academic librarians in view of casting as wide a net as possible regarding the population, concept, and context. Finally, the five-stages method for conducting a scoping review (76, 107) were followed thoroughly, and the rationale for the decisions that were taken was described in detail to provide transparency in line with the recommendation in the five-steps framework. Though a scoping review should have as few limitations as possible, the decisions that were made due to limited time, resources, and so forth, which may be considered as methodological limitations, were also described.

Qualitative study (Study III)

The participants covered a range of topics relevant to the aim of the study. Six to ten participants is considered sufficient to observe relevant patterns in exploratory studies (150). However, given the limited number of participants, the findings cannot be generalized.

Half of the participants were recruited from relatives' associations. The other half was recruited from the larger study, which in both cases may have implications for the transferability of the findings. However, the participants' reflections came from years of experience, including periods during in which there were exceptions to the abovementioned circumstances. By following Guba's (110) four principles to ensure trustworthiness, the findings of the present study may be transferable to populations or contexts similar to those of this study, namely the everyday experiences of partners of individuals with an SUP. We used open-ended questions and provided the participants with sufficient time to respond in order to invite them to share additional reflections in the interviews, which strengthens credibility. By describing both the data-collection and analysis procedures, we ensured transferability. Confirmability was pursued by presenting and discussing preconceived notions about the data within the research team and comparing our findings with those of relevant, peer-reviewed studies. Dependability was strengthened by using the same semi-structured interview guide in all interviews.

7. Conclusions and implications

7.1. Conclusions

This thesis has provided more knowledge on the QoL and everyday experiences of partners to persons with an (SUP) who share care for children.

When exploring QoL and factors associated with QoL among partners to patients with SUDs who share care for children (study I), the participants reported a QoL in line with a general population, but 13% of the total sample reported a markedly low QoL, which indicated that a relatively small proportion of the sample seemed to struggle more with their life situation. For the partners to patients who were referred to treatment, family cohesion was positively associated with QoL, which accentuates the importance of perceived proximity and cohesion in close relations to retain the QoL. Psychological distress was however the strongest variable explaining variations in QoL, which would likely make the partners less able to cope well with a difficult situation.

A summary of the knowledge on QoL of partners to persons with an SUP, obtained in a scoping review (study II), shows that partners scored significantly lower on QoL than general populations. The poor QoL was first and foremost associated with the partner's SUP. When identifying the knowledge gaps regarding the partners' QoL, study II showed that the questionnaires used to measure QoL were adapted to patients or relatives in general and may fail to capture specific areas that are of importance to certain populations, such as partners to persons with an SUP. In addition, many of the studies included in the scoping review report that the partners had minors living in the household, but findings regarding this aspect were reported only to a small degree.

Study III explored how partners of individuals with SUPs describe their everyday experiences, including their parental role. Partners to persons with an SUP describe that living close to a partner with an SUP has an overwhelming negative impact on the circumstances of their everyday lives. Their family roles were altered and this particularly affected their parenting role: instead of having a partner as a co-parent, they sometimes had to protect their children from emotional and/or physical danger imposed by the other parent. The partners of people with SUPs need support in order to handle the significant strains and dilemmas they face but find it difficult to ask for help for fear of stigma. Peer support groups seem to be essential in enabling such individuals to find ways out of their situation.

Partners of individuals with SUP might face a very challenging life situation, and might be in need support for their own sake. In addition, partners being parents to minors, might also be in need of support concerning their children. This thesis highlights the importance of using different research approaches in order to improve the knowledge of a vulnerable group that seems to have been little studied.

7.2. Implications for practice

- Health services should include partners in the treatment and follow-up of individuals with an SUP.
- Brief QoL tools can be used to capture those who struggle most with their life situation, while the context of whether SUP is present in their partner should also be focused on.
- Partners should receive particular attention when they share parenthood of children and should be invited to a conversation in which their possible worries concerning their children are themed.
- Partners should be provided with information about relevant peer support groups.

7.3. Implications for policy makers

- Poor QoL among partners is associated with their partner's SUP, and this should be addressed by policy makers, who need to increase the focus on partners' QoL when patients with such problems are in treatment.
- Partners should be included in the development of national guidelines based on large-scale research, in which also parenting should be included.
- The importance of national guidelines being evidence-based is emphasized; therefore, such evidence must be valid and reliable.

7.4. Implications for future research

- Due to the minority of studies conducted exclusively among partners to persons with an SUP, there is a need for further research examining QoL in this group.
- Gender issues should also be taken into consideration in conducting such studies.
- Currently, the evidence regarding partners' QoL is ambiguous, and there is a need for larger generalizable studies.

- There is a need for more research among partners who also are parents to minors, as their life situation with the SUP of their partner may affect parenting.
- Studies on the effects of implementing supportive measures should be carried out.

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9. Errata list

Page	Line	Current text	New text
Enclosed document, Study I, (published article) page 6, Table 2	1	Table 2 Factors associated with QoL (N = 266)[1]	Table 2 Factors associated with QoL (N = 213)[1]
Enclosed document, Study III, submitted article, page 5, “Recruitment and participants”-paragraph	1	Participants were recruited through the organizations A-Larm and LMS.[2]	Participants were recruited through the organizations A-Larm (n=4) and Landsforbundet Mot Stoffmisbruk (LMS; in English: National Association against Drug Abuse) (n=1), and through the larger study (n=5).[2]

[1] This correction of formal errors concerns the published article “Perceived quality of life in partners of patients undergoing treatment in somatic health, mental health, or substance use disorder units: a cross-sectional study” (Study I in the thesis) which contains the erratum N=266 (Please see p 6, line 1 in the published article). This erratum should be replaced with the correct N=213, which the analyses are based on. This table has however not been reprinted in the thesis.

[2] This correction of formal errors concerns the submitted article “It’s like being stuck on an unsafe and unpredictable rollercoaster – experiencing substance use problems in a partner.” (Study III in the thesis), and has been corrected when describing recruitment in the thesis.

10. Appendices

Paper I

Paper II

Paper III

1. Information about the study and informed consent form for participants in Study I
2. Approval No. 2012/1176A Regional Committee for Medical Research Ethics (Study I)
3. Approval information on the five hospitals participating in the larger study (Study I)
4. Additional project description to Regional Committee for Medical Research Ethics: Interview guide, Information about the study and informed consent form for participants in Study III
5. Approval No. 2012/1176A Regional Committee for Medical Research Ethics, additional approvals (Study III)

Paper I

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Health and Quality of Life Outcomes

RESEARCH Open Access

Perceived quality of life in partners of patients undergoing treatment in somatic health, mental health, or substance use disorder units: a cross-sectional study

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Abstract

Background: This study explores (1) differences in socio-demographic, social/familial, and health variables and perceived quality of life (QoL) among partners of patients with somatic illness, mental illness, or substance use disorder (SUD); and (2) identifies factors associated with QoL.

Methods: Participants (*N* = 213) in this cross-sectional study were recruited from inpatient or outpatient services in five hospitals in Norway, 2013–2014. QoL was measured by the QoL-5, a generic five-item questionnaire. Differences between groups were examined using Chi-square for categorical variables and Kruskal-Wallis for contiuous variables. Multiple linear regression analyses were used to examine factors associated with QoL.

Results: The mean QoL score was similar to that of a general population sample, and 13% of the sample had a markedly low QoL. Partners in the SUD group experienced worse socio-demographic conditions in terms of occupation and income, but QoL did not differ significantly among the three groups. In a regression model, perceived family cohesion was positively associated with QoL while psychological distress (Symptom Checklist-10) was negatively related to it. The model explained 56% of the variance in QoL.

Conclusions: When patients are ill, clinicians should consider the partners' QoL, and brief QoL tools can be used to identify those who are struggling most. Reduced QoL is associated with higher psychological distress and lower family cohesion. Treatment initiatives focusing on these themes may serve as preventive measures to help the most vulnerable families cope with their difficult life situation.

Keywords: Quality of life, Partner, Substance use disorder, Illness, Family cohesion, Social support, Psychological distress

Background

An estimated 30–50% of the general population in Norway will experience a mental disorder in their lifetimes, 10–20% will experience a substance use disorder (SUD), and about 30% will experience cancer [1]. Thus, during their lifetimes, many people will experience an illness of a partner or other loved one across different illness domains. The illness not only will affect the patient but also will impact the partner, and several studies have found that the partner's quality of life (QoL) is negatively affected and typically lower than that of the general population [2, 3]. According to some studies, partner QoL can be even lower than that of the patient [2, 4].

QoL can be affected for several reasons. A loved one's illness may raise concerns and worries about the future [2], which in turn can lead to stress, fatigue, and sleep deprivation [2, 5]. Such factors can influence physical and mental health negatively, and anxiety and depression can be among the consequences [6–8]. Physical and mental health form two integral components of QoL [9, 10], and when they are affected, QoL will typically be perceived as impaired.

Another typical component of QoL is the social domain, or how people rate their social relations [11]. A stressful

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event such as the illness of a loved one can be hard to deal with especially for partners who have no one with whom to share their problems [12–14]. Conversely, higher perceived social support has consistently been associated with higher QoL [2, 3, 14, 15]. Social life within the family is often affected as well; family cohesion may become disrupted, and the partner's familial capacity can be weakened, as when the partner's care is directed towards the needs of the patient at the expense of the needs of children in the household [16, 17]. Several studies have reported correlations between QoL and impaired family life [2, 5, 14].

Studies also have examined the association between socio-demographic variables and the QoL of those who have an ill partner [5–7, 14, 18]. Although there is no obvious reason why gender, for example, would be associated with higher or lower QoL, some studies suggest that the QoL of female partners is more affected than that of male partners [5, 8, 14]. Likewise, other socio-demographic variables and QoL might not be expected to interact automatically – i.e., people can be content with their lives despite difficult life circumstances [9] – but adverse life conditions such as unemployment, higher financial burdens, or poverty would add to the strain when people experience stressful life events such as a loved one's illness. Factors like these could reduce the ability to cope with the situation and in turn negatively affect QoL, as some studies also have suggested [2, 5, 12]. Lack of engagement in work and/or school activity in themselves negatively affect QoL in a normative population [19]. More specifically, partners of mentally ill patients or SUD patients often experience stigma attached to the illness or substance abuse [20, 21], and some may even report overwhelming feelings of guilt and shame [22, 23]. Such additional emotional burdens may cause partners, especially in these two illness domains [24], to withdraw from social networks, further eroding QoL.

In this study, we compared QoL in partners of patients with illness across several illness domains, including somatic health, mental health, and SUD. To our knowledge, no studies have addressed this question by comparing these domains in this way. We hypothesized that:

1. Partners of ill patients would have a lower QoL compared to the normative population.
2. Partners of patients with mental illness or SUD would have a lower QoL compared to partners of patients with somatic illnesses.

The study aims were to (1) explore differences in socio-demographic, social/familial, and health variables and perceived QoL between partner groups and (2) to identify factors associated with QoL.

Methods

Study setting

This study used data from a Norwegian cross-sectional, multicenter study in which the overall objective was to explore the experience of children when one of their parents has an illness, their perceived need for support, and to what extent they receive support. Both parents (the patient and the other parent) were included to give collateral information about the child and to report on their own situation during illness [25]. Thus, the main study consisted of the child, the patient with the illness, and the other biological parent who was or had been the partner of the patient. The study had a broad perspective and set out to examine the children's situations across illness domains within the specialist health care services, i.e., in somatic health (severe neurological conditions or cancer), mental health, and SUD treatment services. Participants were recruited in five Norwegian hospitals. The present study used a subset of these data to examine the sample of partners.

Sample

The partners were recruited via patients in the main study (see above). The patients gave consent to inclusion of partners, and those partners willing to participate gave written informed consent. Respondents were life partners of the patients of the main study, and they shared parenthood responsibilities. As the present study focused on the QoL of partners, we did not include parents that were separated or divorced. Partners who could not read and write Norwegian were excluded.

Of the 534 families included in the main study, 266 partners or ex-partners consented to participate (50%) and 213 (40%) still remained life partner of the patient. In cases of non-inclusion, the patient did not consent to invite the partner to the study or the partner was not willing to participate. The proportion in each category is not known because of insufficient administrative routines, but the inclusion rate in the mental health and SUD illness domains was lower than in the somatic domain (36%, 19%, and 57%, respectively; $\chi^2 = 51.7$, $p < 0.001$).

Data collection

The participants were recruited from March 2013 to December 2014. Recruitment and data collection were carried out by a local coordinator and co-workers at each hospital. Data collection was conducted according to participant choice, usually at their home. Responses to questionnaires that required about one hour to complete were entered on tablets.

Measures and procedures

We included a number of demographic and social indicator variables reflecting living conditions, which may advantageous when examining QoL [26]. In this study, age, gender, work/school status, educational level, and income were examined. Occupation and ongoing education, i.e., work/school status, was summarized into an indicator for activity (percentage engaged in work/school), following the example of Barstad [27].

Social and familial variables

Social support As mentioned, the perceived available social support can be important for how a person copes with a stressful life event and may therefore be an important predictor for perceived QoL in such circumstances. In the analysis, we have placed "social support" and "family cohesion" (see below) under the headings "social/familial variables." Social support was measured using the Interpersonal Support Evaluation List (ISEL), which includes 12 items on social support in both daily life and crises [28]. This instrument is an instrument used to measure the perceived availability of four subscales (Belonging Support, Self-esteem Support, Tangible Support, and Appraisal Support), and the response options range from 1 to 4, with a sum score of 12 to 48; higher scores indicate higher perceived support. There is no generally accepted cut-off for high versus low perceived social support in ISEL. The mid-point of the scale is 30, and scores above that value indicate a more positive than negative view of the amount of social support available [29]. In a US-based general population sample, the mean score was 42.7 (5.0) [30]. The instrument has been used in several countries [31, 32], including Norway [33].

Family cohesion Family cohesion was measured using the Family Cohesion Subscale (FACES-III) [34, 35], with 10 items describing relations among family members and the degree to which family members feel separated from or connected to their family. The responses range from 1 to 5, with a sum score from 10 to 50 and higher scores indicating higher cohesion. A mean score of 39.8 has been found in a general population [36], and a score below 40 indicates perceived lack of cohesion. The Norwegian version has been validated and found to be usable [33].

Partner's perceived family capacity To measure whether the partner's care was directed towards the illness of the patient at the expense of the children and partner's own needs, the main study's project group constructed a set of eight questions for the present investigation. The questions were informed by a qualitative study among Norwegian families with substance use problems [37]. The questions began with the phrase, "Does the condition of the ill parent affect your capacity to…" and were completed with phrases covering eight domains, e.g., "do practical housework," "…give the children emotional support," "…give the children structure," and "…participate in social activities with the children." The questions were scored on a 4-point scale (0 = not at all, 1 = slightly, 2 = to some degree, 3 = to a larger degree). A high score indicates a high influence of the condition/disease on the capacity of the partner in the family. The factor structure of this new scale was examined with an exploratory factor analysis using principal axis and an oblique rotation method (promax). Kaiser's eigenvalue-greater-than-one rule was used to determine the number of factors, and items were retained if they had factor loadings >0.4 [38]. The analysis yielded a univariate solution, and only one factor was extracted; all items had factor loadings above 0.57, and the scale explained 67% of the variance. The Cronbach's alpha was 0.93.

Concerns about child/children The partner's level of concern about their children, i.e., worries about their wellbeing and functioning, was measured using a single question: "Do you have any concerns about your child's wellbeing and functioning?" The question was scaled similarly to the family capacity scale, and a higher score indicated a greater concern for the child. No normative data for this single item exist, as it has been used only in this study.

Health variables

Psychological distress Perceived psychological distress was measured using the Hopkins Symptom Checklist 10 (SCL-10), a short-form of the Hopkins Symptom Checklist 90 [39], which has 10 items about anxiety (4 items) and depression (6 items). Responses were scored on an ordinal scale from 1 to 4, with the highest score indicating highest distress. A total mean score above 1.85 is considered a pathological score, with a mean score of 1.36 in a general population [40, 41]. The SCL-10 assessment is considered to provide a good indicator of psychological distress and is validated and considered suitable for use in Norway [40].

Substance use Substance use and substance use problems in participants were measured with the CAGE questionnaire Adapted to Include Drugs (CAGE-AID) [42]. This instrument includes use of legal and illegal substances, as well as legal substances used in a way other than prescribed. A sum score based on four questions ("yes/no") was calculated (range 0–4), and a score of 2 or higher indicates a substance use problem [42]. A mean score of 0.9 was found in a hospital population sample of non-SUD patients [43]. National guidelines for assessment of substance use in Norway recommend CAGE-AID as an assessment tool [44].

Quality of life (QoL)

QoL was measured with the QoL-5 [45], a generic, validated instrument covering overall QoL, based on an integrative theory of QoL and considered relevant as a disease-nonspecific instrument [45–47]. The reason for choosing the QoL questionnaire was that the instrument has been described as useful for measuring the overall QoL for both general population samples and across different illness domains [45, 46, 48]. It consists of five subjective QoL statements: two questions on mental and physical health, two questions on the quality of the relationship with important others (partner and friends), and one question regarding existential QoL, meaning relation to self. Responses are scored on a five-step ordinal scale ranging from very poor to very good QoL, and then transferred to a decimal scale from 0.1 to 0.9, where 0.9 is the highest/best score and 0.1 the lowest/worst [45, 49]. Mean scores for health, relationships, and existential QoL were calculated, as was a total QoL score as a mean of the three scores. A mean score of 0.69 was found in a previous survey of the general population and was used as our population reference [45]. The cut-off score for a markedly low QoL has been suggested to be −0.15 below the general population (<0.55) [47]. The instrument has been used in a number of studies and is sensitive to QoL changes and for capturing differences in QoL; it has also been established as a valid and reliable instrument [45, 47, 50].

Statistical analyses

Descriptive statistics were used to present sample characteristics. Differences between groups were examined using Chi-square for categorical variables. The Kolmogorow-Smirnov test was implemented to ascertain whether continuous variables were or were not normally distributed. Since the criteria for a normal distribution were not fulfilled, the nonparametric Kruskal-Wallis test was used for the inter-group comparisons. If significant, results were followed up with a Mann-Whitney U-test. Before the multiple regression analysis, preliminary bivariate analyses were used to examine factors associated with QoL; factors with a p value below 0.20 were included in the following sequential procedure following the lax criterion recommended by Altman [51]. A stepwise procedure (hierarchical regression) was used to examine the relative influence on QoL of socio-demographic, social/familial, and health variables. In the first step, we included socio-demographic variables (group, gender, education, work/school activity, and income). In the second step, we included social/familial variables (family cohesion, social support, concern for child, and whether the familial capacity was influenced by the illness). Finally, in the last step, we added health variables (psychological distress). The dependent variable (QoL) was expected to be skewed toward the higher end of the scale; thus, a bootstrapping procedure (1000 replications) was used to obtain more robust estimates. Results are presented as unstandardized beta coefficients with 95% confidence intervals (CIs). The R square (R^2) value was used to assess the fit of the statistical model. Analyses of variables were considered to be statistically significant at $p < 0.05$. All analyses were performed using IBM SPSS Statistics version 21.

Results

Differences between partner groups

The total sample consisted of 213 partners: 116 in the somatic illness domain, 72 in the mental illness domain, and 25 in the SUD domain (Table 1). We found significant differences across groups. The proportion of women was higher in partners in the SUD group. Partners in this group also reported having significantly lower income, lower education level, and less work/school activity.

The mean score on the family cohesion scale (FACES-III) was above the cut-offs for lack of cohesion and on the positive side of the social support scale (ISEL). The partners' perceived capacity in the family was affected only modestly by the illness of the patient, as evidenced by a mean score close to the term "slightly affected" on the scale. There were no significant differences across groups in these variables. In terms of concern for the child/children in the family; the participants had little worry for the child (a mean score of ≤1 on the scale), with the lowest score in the SUD group.

In terms of health variables, only 7 (3%) scored above the cut-off the for severe substance use problems (CAGE-AID), with a slightly higher proportion of problematic substance use in the SUD partner group. Regarding perceived psychological distress (SCL-10), the mean score (1.44, SD 0.50) was below the pathological cut-off for all three groups, with 39 (18%) participants scoring above the cut-off for psychological distress. No differences in perceived psychological distress (SCL-10) emerged among the three groups.

QoL scores were similar to those of the normative population for the sample as a whole (0.71, SD 0.14), with no significant differences among groups (Table 1). A small proportion of the sample (13%) reported a markedly low QoL (<0.55).

Variables associated with QoL

In bivariate analyses, age and substance use (CAGE-AID) had p-values above the recommended lax criterion ($p > 0.2$); thus, they were excluded from further analyses and from the following model.

The first step of the hierarchical regression (socio-demographic variables) (Table 2) showed that income and work/school activity were significantly associated with QoL. This model explained 6% (R^2) of the variance. In the second step of the hierarchical regression, we added social/familial variables; family cohesion (FACES-III), perceived social support (ISEL), and perceived worry/concern about the child/children were significantly associated with QoL (Table 2). This model explained 33% (R^2) of the variance in QoL. The final model included health variables,

Table 1 Characteristics of participants (*N* = 213), with data presented as N (%) or *mean (SD) / median (Interquartile range, IQR) [italics]*

Variables	Somatic group (A) *N* = 116	Mental illness group (B) *N* = 72	Substance use (SUD) group (C) *N* = 25	Total *N* = 213	*p* value[a]	A / B[b]	*A / C*[b]	*B / C*[b]
Age, years	*43 (7)/ 43 (9)*	*39 (8)/ 38 (15)*	*36 (10)/ 35 (15)*	*41 (8)/ 41 (12)*	<0.001	0.004	0.001	ns.
Gender, women	35 (30)	13 (18)	16 (64)	100 (38)	<0.001	ns.	0.001	<0.001
Work/school activity[c]	89 (26)/ 109 (94)	85 (33)/ 63 (88)	52 (46)/ 15 (60)	83 (33)/ 187 (88)	<0.001	ns.	<0.001	0.003
Educational level								
- Primary education	13 (11)	5 (7)	6 (24)	24 (11)				
- High school	37 (32)	36 (50)	14 (56)	87 (41)	0.003	0.044	0.003	0.023
- College/university	66 (57)	31 (43)	5 (20)	102 (48)				
Income[d]	*986' (439)/ 900' (380)*	*770' (271)/ 700' (250)*	*481' (224)/ 450' (210)*	*849' (403)/ 800' (385)*	<0.001	<0.001	<0.001	<0.001
Social support (ISEL)	*38.2 (6.2)/ 38.5 (10.8)*	*37.3 (7.3)/ 37.0 (10.8)*	*37.2 (6.9)/ 38.0 (13.0)*	*37.8 (6.7)/ 38.0 (10.0)*	0.767			
Family cohesion (FACES-III)	*42.3 (5.4)/ 43.0 (8.0)*	*41.4 (5.9)/ 42.0 (9.8)*	*40.6 (8.0)/ 41.0 (9.5)*	*41.8 (6.0)/ 43.0 (9.0)*	0.649			
Perceived family capacity influenced by patient's illness[e]	*0.9 (0.8)/ 0.8 (1.5)*	*1.2 (1.0)/ 1.0 (1.8)*	*1.0 (0.9)/ 0.6 (1.5)*	*1.0 (0.9)/ 0.9 (1.5)*	0.053			
Perceived concern for children[f]	*0.9 (0.9)/ 1.0 (2.0)*	*1.0 (1.1)/ 0.0 (2.0)*	*0.4 (0.8)/ 0.0 (0.0)*	*0.8 (1.0)/ 0.0 (2.0)*	0.036	ns.	0.013	0.017
Substance use (CAGE-AID), cut-off >2	2 (2)	2 (3)	3 (12)	7 (3)	0.031	ns.	0.012	ns.
Perceived psychological distress (SCL-10)	*1.42 (0.43)/ 1.30 (0.68)*	*1.49 (0.58)/ 1.30 (0.80)*	*1.40 (0.55)/ 1.20 (0.40)*	*1.44 (0.50)/ 1.30 (0.70)*	0.877			
Quality of Life (QoL-5)	*0.72 (0.13)/ 0.73 (0.17)*	*0.68 (0.16)/ 0.68 (0.23)*	*0.73 (0.13)/ 0.73 (0.20)*	*0.71 (0.14)/ 0.70 (0.23)*	0.122			

[a] *p* value obtained from Chi-square tests or Kruskal-Wallis

[b] When the three group tests were significant, results were followed up with paired comparisons. *p* value obtained from Chi-square or Mann-Whitney U-test. The term ns. means non-significance

[c] Percentage engaged in work/school

[d] Income in 1000 NOK

[e] Scale 0–3; higher score indicates that the condition of the ill parent had a higher impact on the other parent's family capacity

[f] Scale 0–3; higher score indicates a higher concern for the child's/children's situation

and only two variables were significantly associated with QoL: perceived family cohesion and psychological distress. Perceived family cohesion was positively associated with QoL while psychological distress (SCL-10) was a negative predictor (beta = −0.16; 95% CI = −0.20/−0.13, $p < 0.001$; Table 2). The final model explained 56% (R^2) of the variance in QoL (Table 2).

Discussion

Some socio-demographic variables differed significantly among the groups in this study; partners in the SUD group differed significantly in terms of gender (being female), lower work/school activity, lower educational level, and lower income. The QoL score for the total sample was similar to that of a normative population sample, with no significant differences in QoL among groups. In a regression model, perceived family cohesion was positively associated with QoL whereas psychological distress was negatively related to it. The model explained 56% of the variation in QoL.

The normality of the QoL scores in this population was unexpected in light of the known strain of having an ill partner [8, 12, 14, 18]. Previous studies among partners to ill patients showed that if the patient received treatment, the impact on the partner's QoL was positive [8, 52, 53]. Our participants were recruited during a treatment period for the ill parent, which may in part explain the unexpectedly high QoL in our sample. However, in the long run, treatment does not necessarily lead to a better QoL in the partner if the patient does not have a remission [6, 53, 54]. Nonetheless, 13% reported a markedly low QoL. This finding indicated that a relatively small proportion of the sample seemed to struggle more with their life situation.

The lack of significant differences in QoL between groups was also surprising and was contrary to our hypothesis. The partners in the SUD group were worse off in terms of some socio-demographic conditions; for example, they were less likely to being occupied with work or school, and had a poorer educational level and income than the other two

Table 2 Factors associated with QoL ($N = 266$)

Variables	Block 1[b]		Block 2[b]		Block 3[b]	
Socio-demographic variables	B (95% CI)	*p* value[a]	B (95% CI)	*p* value[a]	B (95% CI)	*p* value[a]
Group[c]	0.02 (−0.01/0.05)	0.141	0.02 (−0.01/0.04)	0.242	0.00 (−0.02/0.03)	0.715
Gender	−0.02 (−0.07/−0.02)	0.279	−0.03 (−0.07/0.01)	0.141	−0.01 (−0.04/0.03)	0.758
Education	0.01 (−0.02/0.04)	0.431	0.01 (−0.02/0.04)	0.498	0.00 (−0.02/0.03)	0.760
Work/school activity[d]	0.00 (0.00/0.00)	0.050	0.00 (0.00/0.00)	0.241	0.00 (−0.00/0.00)	0.669
Income[e]	0.01 (0.00/0.01)	0.030	0.00 (−0.00/0.01)	0.180	0.00 (−0.00/0.01)	0.437
Social / familial variables						
Family cohesion (FACES-III)[f]			0.05 (0.02/0.08)	0.003	0.05 (0.02/0.07)	0.001
Social support (ISEL)[g]			0.07 (0.03/0.10)	0.001	0.03 (−0.00/0.06)	0.091
Concern about child			−0.03 (−0.05/−0.01)	0.002	−0.01 (−0.03/0.01)	0.206
Family capacity			−0.01 (−0.04/0.01)	0.186	−0.01 (−0.02/0.01)	0.558
Health variables						
Psychological distress (SCL-10)					−0.16 (−0.20/−0.13)	<0.001

[a] *p* value obtained from multivariate linear regression, presented as beta and 95% confidence interval (CI)

[b] Explained variance (R^2): Block 1 (socio-demographic variables) = 6%; Block 2 (social/familial variables) = 33%; Block 3 (health variables) = 56%

[c] Groups: Partners of patients in three domains – somatic or mental illness or substance use disorders

[d] Percentage engaged in work/school activity

[e] Income in NOK 100,000

[f,g] Mean scores were used to facilitate interpretation of the coefficients

groups, but these findings were not reflected in a poorer QoL at the group level. In general, poorer socio-demographic conditions seem to affect QoL negatively [9]; however, the subjective experience of such conditions affects QoL more than the 'objective' differences [55]. Thus, in line with other research [56, 57], overall QoL is more than a measurement of objective demographic conditions; it reflects how the individual relates to these conditions. An alternative explanation may be that when the patient receives treatment, a partner in the SUD group experiences a relatively greater relief from worries and burdens and perhaps perceives a temporal relief from their worries [54]. Thus, their QoL score may have been overestimated at this specific point in time.

Family cohesion were retained as significant factors associated with QoL in the final regression model. This outcome has been seen in previous studies among partners of patients with illness and accentuates the importance of perceived proximity and cohesion in close relations to retain the QoL [2, 14, 54]. The experience of instability and insecurity that partners of ill patients report may affect perceived family cohesion and also underlie the negative influence on QoL [5, 14].

Psychological distress (SCL-10) was the strongest variable explaining variations in QoL. A one-point gain (higher psychological distress) resulted in a 0.16 lower QoL-5 score in the final adjusted model, suggesting a substantial influence when applying the clinical interpretation of the scale [46]. The fit of the model was also strengthened considerably, and the explained variance in QoL increased from 33% to 56% with inclusion of this clinical variable. Feelings of hopelessness, worry, stress, and depression have been observed in partners of somatic or mentally ill patients [12, 18], as has anxiety in relatives of SUD patients [4, 6]. Such negative emotions may underlie the psychological distress reported here, which in turn strongly predicted worse QoL. High psychological distress would likely make an individual less able to cope well with a difficult situation arising when a close relative suffers from an illness. Other studies also report strong correlations between psychological distress and poor QoL [2, 6–8, 52], affirming the findings of our final model. However, with the present design, we cannot discern whether the reported psychological distress existed before the illness or was a reaction to having an illness in the family.

Methodological considerations

The strengths of the study include an acceptable sample size and inclusion of groups of respondents who have not been compared before; previous studies tend to focus on separate domains. However, some limitations must be kept in mind. The sample size per group may not have been large enough for detecting statistical significant differences between them. Furthermore, the participants were recruited while the ill parent was in treatment, which might limit the representativeness of the findings. The participants in most benchmark studies in this field have an average age at least 10 years greater than in our study [7, 8, 12–14, 53]. The sample is therefore mainly representative of middle-aged partners and time periods when the ill parent is enrolled in treatment. Although socio-demographic variables differed among the groups, the findings indicate that we did not recruit respondents with extreme economic or social disturbances in their lives. One possible question is if those who did not participate experienced more disturbances compared to those who did [12]. The attrition analysis showed that there was a lower inclusion rate in the mental health and SUD illness domain, indicating that our results may be positively biased in these two illness domains. Further attrition analysis was not possible because administrative data on non-inclusion were insufficiently registered. The limited sample size per group also prevented us from examining whether there were different associations between independent variables and QoL across groups, i.e. with separate regression analyses for each group. In spite of the limitations, the findings provide important information about obstacles and facilitators of QoL in partners, which may be informative for further research and interventions.

Implications

Although the findings indicate that the sample as a whole reported a QoL score in line with the general population, some respondents still reported a markedly low QoL. We suggest that such brief QoL tools can be used to capture those who are struggling most with their life situation.

Conclusions

Treatment services should include consideration of the partners in times of illness of patients, and short QoL assessments can be one way of identifying those with a need for particular support. For these partners, the findings of the present study suggest the most important themes that clinicians should address: family cohesion and psychological vulnerability. Treatment initiatives focusing on these themes may serve as preventive measures to help the most vulnerable families cope with their difficult life situation.

Abbreviations

CAGE-AID: CAGE (acronym) questionnaire Adapted to Include Drugs; FACES-III: Family Cohesion Subscale; ISEL: Interpersonal Support Evaluation List; QoL: quality of life; SCL: Symptom Checklist; SUD: substance use disorder

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Availability of the data and materials

The data used in this study form the basis of ongoing PhD and postdoctoral studies. The data will be anonymized 31.12.2019 and according to current Norwegian regulations and practice, they may be deposited to a publicly available data repository afterwards.

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Authors' contributions

BB participated in the design of the study and data collection; in addition, BB performed the analysis, interpreted results, and drafted the manuscript. BW participated in the design of the study, data collection, interpreting results, and drafting the manuscript. TR conceived the study, its design, and the research protocol and helped with interpreting results and drafting the manuscript. MMH participated in interpreting results and drafting the manuscript. JKV participated in performing the analysis, interpreting results, and drafting the manuscript. All authors read and approved the final manuscript.

Ethics approval and consent to participate

All procedures performed were in accordance with the ethical standards of the national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study was approved by the Regional Committee for Medical Research Ethics (REK), Approval No. 2012/1176 A.

Informed consent was obtained from all individual participants included in the study.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Paper 2

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REVIEW Open Access

The quality of life when a partner has substance use problems: a scoping review

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Abstract

Objective: To examine the existing body of knowledge on quality of life (QoL) in partners of people with substance use problems (PP-SUPs) to provide a synthesized summary of the evidence and identify gaps in our knowledge on the QoL of PP-SUPs.

Methods: A systematic scoping review was performed. Publications indexed in EMBASE, Medline, PsycINFO, CINAHL, SocINDEX, and CENTRAL were searched for original, empirical, peer-reviewed, full-length research papers that examined QoL in PP-SUPs. Research papers identified through a manual search of key references and known references by co-authors were also included. A total of 3070 abstracts were screened, 41 full-text papers examined, and nine were found to meet the inclusion criteria. Eligibility was determined in two steps by four and two independent researchers, respectively. The main findings were explored by content analysis.

Results: Eight of the nine included studies had quantitative designs, one had a mixed methods design, and no qualitative studies were found. Three studies were conducted exclusively among PP-SUPs, whereas the others included various subgroups. A majority of participants were women, and no study was conducted exclusively among men. Nearly half of the studies reported on whether there were minor children in the PP-SUPs' household. The studies used established and generic QoL instruments based on different conceptual and theoretical perspectives on QoL. A majority of the studies found lower QoL in PP-SUPs than in general population, with substance use by the person with a SUP having the most impact on QoL of all evaluated factors. Two studies reported that gender was associated with QoL, with poor QoL being associated with being a male partner and vice versa for female partners.

Conclusions: Further research is needed to examine QoL in PP-SUPs exclusively. A variety of QoL instruments covering various, but limited, dimensions of the concept have been used in previous studies of PP-SUPs. Thus, obtaining a comprehensive understanding of PP-SUPs' QoL is challenging. Both qualitative and large-scale quantitative designs should be used in research on QoL in PP-SUPs, particularly among those with a parenting role.

Keywords: Quality of life, Partners, Substance use

Background

Substance use problems (SUPs) affect the health and well-being of not only the person with the problem, but also their partners and families [1–3]. Substance use problems relate to consequences of substance use, such as physical and/or mental injuries, social and/or interpersonal problems, neglected major roles, and/or legal problems [4], and include a range of substances such as alcohol, opioids, cannabis, amphetamine/meth-amphetamine, and addictive drugs/medicines [5, 6]. Being the partner of a person with SUP involves being influenced by the consequences mentioned above. This study focuses on partners' perspective on the SUP of the person with the problem, and hence the term substance use problem (SUP) is chosen over the diagnostic term 'substance use disorder' [6]. From the partners' perspective there might exist a SUP when the use of substances disrupts the person's tasks and functions that are to be taken care of in the family and / or interferes with the

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relationships between people [7]. Partners might experience the person with a SUP as having physical,- emotional,- and/or relational problems; problems at work or school; with the police because of the use of substances; or spending a lot of time using substances, or recovering from a hangover [8]. In Norway, Ireland and Australia, an estimated 10–30% of relatives, including partners, are affected by SUP in a close family member based on prevalence studies [5, 9, 10]. These problems may negatively affect various areas of relatives' lives, such as poorer mental or somatic health [1, 8], social isolation, and poorer family conditions [11, 12]. Studies have also shown reduced lifespan (years of life) in close relatives of people with SUPs [1, 13]. In addition, studies report poorer socio-demographic conditions in close relatives: poverty, drop-out from school or work [1, 13, 14], and lower education levels have been reported in partners of persons with SUPs (PP-SUPs) compared to the general population [8].

The life areas reported above are essential dimensions of quality of life (QoL) in individuals, groups, and populations. Examining QoL can provide a broader perspective on individuals' total situation than a more narrow focus on, for example, health or financial outcomes [15]. Understanding and assessing QoL in different populations may serve as a basis for the development of knowledge-based measures to promote health and prevent possible negative outcomes in different areas of QoL in vulnerable populations, such as PP-SUPs. Studies investigating QoL have increased in recent years. The concept, however, has been defined in various ways and not always clarified or defined when used in research; therefore, QoL measures can differ across contexts. Barcaccia et al. [16] analyzed the concept of QoL in their review and concluded that psychological, spiritual, and social dimensions should be included in addition to dimensions strictly related to physical health when evaluating QoL. These dimensions, understood as inherent in the QoL concept, are in line with previous definitions: physical, psychological, social, and relational dimensions [17], as well as environmental and existential dimensions [18, 19]. Environmental dimensions may be understood in line with Moons et al. [20], who described living condition domains, such as economy, housing, and security. Together, all these dimensions (i.e., physical, psychological, social, relational, spiritual/existential, and environmental) may constitute a more comprehensive understanding of the concept of QoL and is the perspective on QoL that informs this review.

There has been an increase in the number of studies examining QoL in which a key aspect is a subjective, self-reported assessment of QoL [16]. Many measurements have been developed to measure QoL. As each measure focuses on different dimensions [21], QoL measures are not homogenous. The health-related QoL measure Short Form 36 (SF-36) [22] measures physical and mental health and considered a generic measure across illness states [23]. Though the SF-36 measures the individual's internal capability of life, other measures, such as the WHOQOL-BREF [18], measure inner life satisfaction or subjective enjoyment of life [24]. This indicates that health-related QoL measures tend to be more objective than subjective (as they ask questions such as whether the person has difficulty with mobility) than other measures such as rating of psychological well-being.

Relatives of persons with SUPs, including partners, have been recognized as an underserved population in healthcare [25], and QoL assessments can be useful in identifying those who struggle the most and need support or follow-up [15]. Examining the QoL of PP-SUPs will provide knowledge of their overall situation. Reviewing which QoL dimensions have been covered in studies of PP-SUPs' quality of life will provide evidence on knowledge gaps that require further investigation. Synthesized knowledge on QoL in partners may serve as the basis for preventing negative outcomes, such as burdens and health risk, both for the partners and other relatives or family members (i.e., children) [8], as well as interventions to improve their well-being and QoL. Mapping (i.e. summarizing the range of evidence to describe breadth and depth) of the research field [26] regarding QoL of PP-SUPs will contribute to a broader picture of their situation. To the best of our knowledge, synthesis and summary of this evidence has not been conducted previously. Therefore, the overall aim of this scoping review was to examine the extent, range, and nature of the body of knowledge on QoL in PP-SUPs for the purpose of providing a synthesized summary of the evidence and to identify gaps in our knowledge of the QoL of PP-SUPs**.** The research questions are: 1. How has quality of life been investigated and measured with respect to PP-SUPs?, and, 2. How do PP-SUPs report their quality of life?

Methods

A scoping review was conducted in collaboration with two experienced librarians (J.H. and E.S.) using systematic search methods. Scoping reviews have been used increasingly in health services research during the past few years [26, 27], as they are a suitable method in areas in which little research exists, or when existing studies appear heterogeneous in their results and conclusions. Systematic scoping reviews require formal methods but differ from other reviews in some ways. First, a scoping review aims to examine the extent, range and nature of the body of literature of a specific topic in a broader perspective and does not necessarily assess the quality of the included studies. Second, scoping reviews are suitable for identifying research gaps and may also provide a mechanism for summarizing and disseminating research findings to policymakers and health care providers. Identifying gaps may also lead to more research in a particular field [26, 28]. Due to a lack of a summary of knowledge on the QoL of PP-SUPs, such broad mapping is suitable for enabling an overview of the knowledge status in this area.

The choice of review method was also informed by initial searches in Google Scholar, followed by initial searches of the literature in two databases: EMBASE and PsycInfo. This search showed that studies investigating QoL in PP-SUPs were limited. To a large degree, studies were conducted among persons with SUPs, with a secondary aim to include their family members [29, 30]. The results reflecting QoL in these studies were also different and ambiguous and did not necessarily specify the rationale for using the same QoL instruments across the included subgroups of participants (i.e., patients and family member, herein also partners) [29, 30].

In order to map the broader literature, there was an agreement to include articles with multi-dimensional perspectives on QoL. There was also an agreement to extract associations with QoL that were statistically significant (i.e. 95% Confidence level.The approach for conducting systematic scoping reviews by Levac et al. [26] was used to guide the review based on the five-stage methodological framework developed by Arksey and O'Malley [28].

Stage 1: Identifying the research question

The central questions guiding this scoping review were:

1. How has quality of life been investigated and measured with respect to PP-SUPs?
2. How do PP-SUPs report their quality of life?

Stage 2: Identifying relevant studies

After the initial search in EMBASE and PsycInfo, six electronic databases were searched: EMBASE, Medline, PsycINFO, CINAHL, SocINDEX, and CENTRAL, with the last searches performed on June 23, 2017. No date limits were set. The search strategy included specifications of the *context* (substance use problems), *participants* (partners), and *concept* (quality of life) [31]. The search terms were then further identified. The *context* terms consisted of alcohol abuse, drug abuse, and drug dependence, with subgroups and different combinations. The *participants* terms consisted of partner, spouse, and significant other, also with subgroups and different combinations. The *concept* term consisted of quality of life, well-being, and life satisfaction.

Table 1 presents the search strategy that was used for EMBASE, which was adapted in minor ways for the other databases.

Stage 3: Study selection

Inclusion criteria

Quantitative and qualitative peer-reviewed, original, full-length research papers were included. Research papers identified through a manual search of key references and references known by co-authors were also included. The overall aim included summarizing knowledge status; thus, study protocols and conference papers in which the results had not been published in peer-reviewed journals were excluded. Because of limited time and resources, articles presented in languages other than English were also excluded. In addition, intervention studies and empirical papers which were not peer-reviewed were excluded.

Participants

The participants were present partners to persons with SUPs. The population may have been examined exclusively in "pure" partner studies, or as a subsample in a total sample of close relatives.

Concept

The key concept that was reviewed was the self-reported quality of life, including multidimensional dimensions, where at least physical and psychological health domains and social/relational domains occur.. Studies that had a very narrow focus on well-being, e.g., psychological distress only, were excluded.

Context

The context of the participants in the various studies was being a present PP-SUP. The substance use was characterized or described as problematic, heavy, or severe, or in terms of a medical diagnosis, and as the main condition. The context may or may not include a treatment situation.

Search strategy

When performing the search strategy in the six different databases, a total of 4419 records were identified. These records were exported into EndNoteX8. Four records were identified through other sources, such as manually searching key references and feedback from co-authors. Duplicate records were then removed, resulting in 3070 records for screening the title and abstract. The screening was performed by two authors (BW and BB), who independently compared the titles and abstracts of each record with the inclusion criteria. BW and BB finally agreed to include 41 records as relevant studies for full-text screening. The records considered eligible for full-text screening were then distributed among two other authors, AS and MH, in addition to BB and BW, who independently screened the full-text studies to assess eligibility for inclusion in the review. One author (BB) screened the reference lists of the included studies. Of the 41 articles considered for inclusion, there was agreement on 36 (88%). In cases in which there was disagreement or doubt (12%), discussion meetings were held until an agreement was reached. In some cases, one of the other authors was consulted. Of the 41 screened full-text articles, 32 were excluded with reasons. The majority of these articles were excluded because the participants did not represent the relevant group (i.e. the persons with SUP had other main illnesses or conditions), they did not specifically present the results for the PP-SUP, the focus on well-being did not match our criteria for QoL, or well-being was measured in a very narrow way with, for example, only one QoL domain included. (e.g. stress, or well-being measured by using a depression scale only). This was also the case for the excluded qualitative articles, which in most cases focused on coping strategies as a measure of well-being. These articles were considered to diverge too much from the QoL domains. A total of nine articles were finally included in the review (Fig. 1).

Table 1 Search strategy

Substance use problems (context):

1 exp. Alcohol abuse/ (30694)

2 exp. Drug abuse/ (98077)

3 Substance abuse/ (48562)

4 Alcoholism/ (112452)

5 exp. Drug dependence/ (205497)

6 ((drug* or substance* or alcohol*) adj2 (misus* or abuse* or addict* or depend* or overuse or problem* or “use disorder*”)).tw. (158120)

7 ((opioid* or opiate* or opium or narcotic* or polydrug? Or heroin) adj2 (misus* or abuse* or addict* or depend* or overuse or problem*)).tw. (20773)

8 (alcoholi* or “excessive alcohol use” or “drinking problem?” or “heavy drinking” or “binge drinking”).mp. (180840)

9 ((beer or wine or liquor or spirits) adj (misus* or abuse* or addict* or depend*)).tw. (36)

10 or/1–9 (418874)

Partners (participants):

11 exp. Spouse/ (13557)

12 spous*.tw. (20290)

13 exp. Marriage/ (57950)

14 (marriage or “marital relations”).tw. (16392)

15 (couple or couples*).tw. (68126)

16 cohabit*.tw. (4618)

17 “next of kin”.tw. (1650)

18 (partner* or “other parent”).tw. (175877)

19 (wife* or wives* or husband* or widow*).tw. (28711)

20 “loved one*”.tw. (3646)

21 ((significant or concerned) adj other*).tw. (4377)

22 exp. Caregivers/ (58055)

23 (caregiver* or care-giver* or “care giver*” or carer*).tw. (79780)

24 (codependen* or co-dependen*).tw. (1120)

25 Family/ (88179)

26 famil*.ti. (230468)

27 exp. Parent/ (208855)

28 (parent* or mother* or father* or paternal or maternal).tw. (821969)

29 or/11–28 (1431510)

Well-being (concept):

30 exp. “Quality of Life”/ (384374)

31 (quality adj2 life).tw. (324553)

32 (wellbeing or well-being or “well being”).tw. (82479)

33 exp. Life satisfaction/ (7834)

34 (satisfact* adj2 life).tw. (9640)

35 (SEQOL or QOL or HRQL or WHOQOL* or EUROQOL*).tw. (62092)

36 30 or 31 or 32 or 33 or 34 or 35 (519733)

Combined search:

37 10 and 29 and 36 (1468)

Stage 4: Charting the data

Quality of life issues related to PP-SUPs were analyzed by three authors (BB, BW, and KF) using steps from qualitative content analysis [32], including three main phases: preparation, organizing, and reporting. For this task, a structured data tool was used. One author (BB) extracted additional study characteristics, which were also reviewed by BW and then included in agreement between BB and BW. As this was a scoping review, study quality (e.g., risks of bias, study strength) was not considered [28]. The tables show the systematization and categorization of relevant topics from the results of the studies included in this review, reflecting the review questions.

Stage 5: Collating, summarizing, and reporting the results

The main characteristics of the nine included studies are presented in Table 2. The studies were grouped by year of publication. Studies published in the same year were grouped in alphabetical order of first authors’ surnames.

Findings

The findings of the review are presented according to the review questions. Table 2 reports the general information and major findings of the reviewed publications.

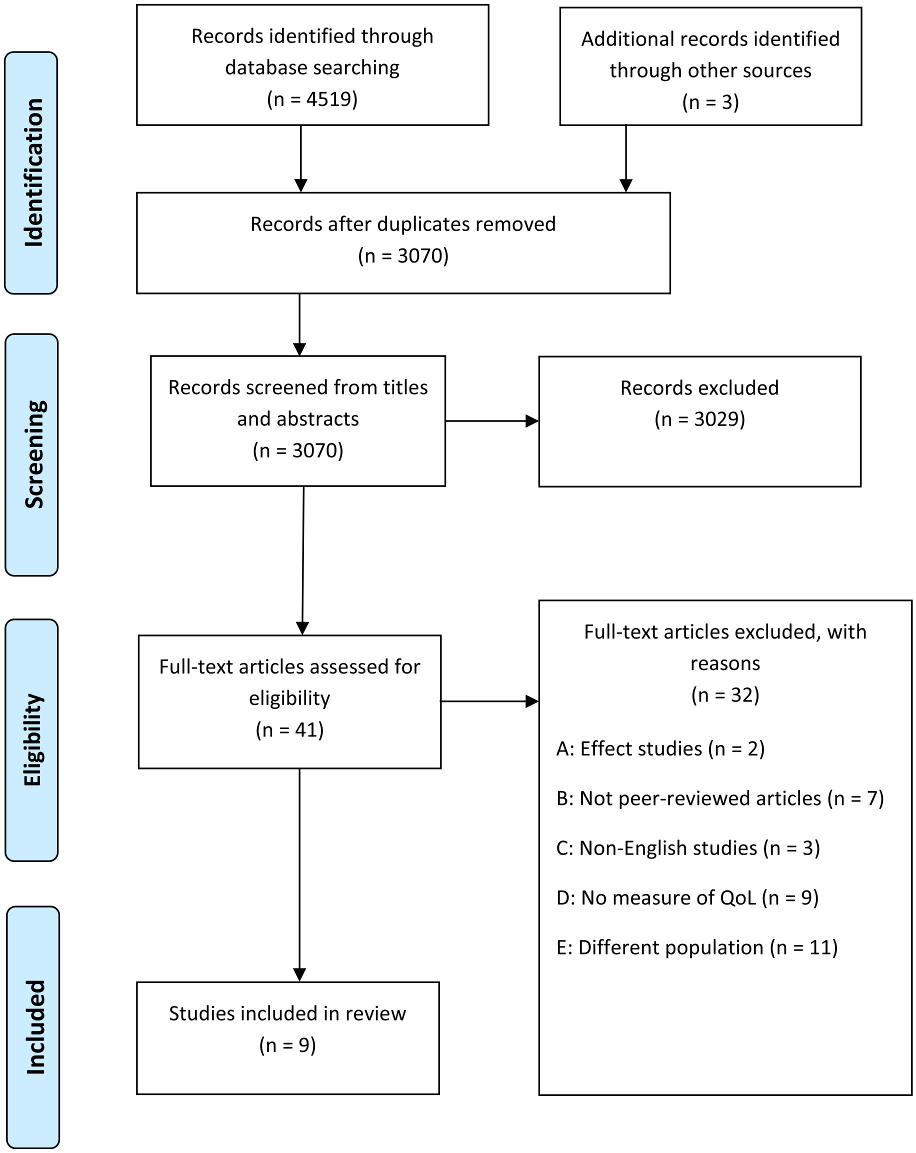

Fig. 1 PRISMA flowchart

How quality of life of PP-SUPs has been investigated and measured

Three of the nine included studies were conducted in Australia [33–35]. The remaining studies originated from Canada [36], New Zealand [37], the Netherlands [30], USA [8], Croatia [29], and Spain [38]. The studies were spread over a wide timeframe, with two studies published before 2000 [35, 36] and seven published after 2010. The majority of the studies aimed to examine the impact of SUPs on close family members, with QoL as one of the primary outcomes. In four of the studies, the participants were recruited when their partner was in treatment [29, 30, 36, 38], in one study the participants were recruited through newspaper advertisements [35], and in one study the participants were recruited in mutual aid support groups (Al-Anon Family Groups and FDH, a program of the Self-Help Addiction Resource Centre (SHARC), both in Australia) [34].

Methods

Eight of the studies had a quantitative design. Three studies were larger, general population surveys [8, 33, 37]. One was a case-control study [29], and four had a cross-sectional design [30, 35, 36, 38]). One of the studies had a mixed methods design in which QoL was included in the qualitative part [34]. No purely qualitative studies were found that met the inclusion criteria.

Table 2 Studies examining QoL in partners to persons with substance use problems

Reference, year, and country	Aim and methods	Sample size and population	Type of substance use in the person with SUP	Test method for associations between having a partner with SUP and own QoL	Controlled for own SUP in PP-SUP in estimations of associations with QoL	QoL perspectives from results section
1. Brown et al. [36] 1995 Canada	To explore gender differences in married substance abusers admitted to treatment, particularly with a view to clarifying the relationship between client functioning and that of the spouse. Cross-sectional study QLQ (Quality of life Questionnaire)	*N* = 85 Gender of partners: 67 female and 18 male Mean age of partners: 37 years	Substance abuse (alcohol and other drug use)	Not performed	Not controlled for	Gender differences in partners' QoL, with men scoring significantly lower on: • physical well-being • parent-child relations (less involvement with children and poorer parenting) • altruistic behavior (inability to provide support to others)
2. Barber et al. [35] 1997 Australia	To identify whether some coping responses are more likely than others to be associated with psychological adjustment in the partners of drinkers A multiple regression study Wolcott & Glazer's 12-item Well-being scale	*N* = 60 Gender of partners: 57 women, 3 men Mean age of partners: 45 years	Heavy drinking	Standard multiple regression	Not controlled for	• No association between the use of negative behaviors towards the drinker and psychological well-being, irrespective of being used when the partner is drunk or sober • Negative behaviors towards the drinker when sober were marginally negatively related to psychological well-being • Positive behaviors towards the drinker had a marginally significant correlation with well-being
3. Dawson et al. [8] 2007 USA	To examine the association between partner alcohol problems and select physical and mental health outcomes among married or cohabiting women, before and after adjusting for potential confounders, and to compare these associations with those reflecting the impact of the women's own alcohol-use disorders A cross-sectional, retrospective survey of a nationally representative sample of U.S. adults 18 years of age and older. Short Form-12 Health Survey Questionnaire,	11,683 married or cohabiting women (PP-SUPs) Mean age of partners: 42 years	Alcohol problems	- Unadjusted (bivariate) regression models constructed to estimate the magnitude and significance of the associations between partner alcohol problems and the health outcomes. - Linear regression models for associations between numbers of stressors and QoL-scores.	Controlled for	• Significantly lower psychological QoL scores in women whose partners had alcohol problems • No significant difference in physical QoL between women with and without partner alcohol problems • Lower psychological QoL was significantly associated with higher level of own alcohol use of the participants • Partner alcohol problems were significantly associated with higher probability of being in fair or poor health and a lower mean

Table 2 Studies examining QoL in partners to persons with substance use problems *(Continued)*

Reference, year, and country	Aim and methods	Sample size and population	Type of substance use in the person with SUP	Test method for associations between having a partner with SUP and own QoL	Controlled for own SUP in PP-SUP in estimations of associations with QoL	QoL perspectives from results section
	Version 2 (SF-12v2)-based physical quality of life. SF-12v2-based mental/ psychological quality of life					psychological QoL scores
4. Casswell et al. [37] 2011 New Zealand	A first step in investigating relationships between exposure to heavy drinkers in respondents' lives with measures of health status and well-being A cross-sectional general population survey European Quality of Life-5 Dimensions (EQ-5D) Personal Well-being Index (PWI)	*N* = 3068 (total sample) 29% had a heavy drinker in their lives Partners to heavy drinkers: 15% Mean age of partners: Not reported Gender of partners: Not reported (but for total sample 1232 males, 1836 females).	Heavy drinking	Proportional odds model used to predict relationship	Controlled for, but not reported on PP-SUPs exclusively	• Three-quarters of respondents who had a heavy drinking partner were in the highest exposure group (i.e., they were exposed to three or more heavy drinkers) • QoL in PP-SUP not reported • Women reported higher QoL than men • Poor QoL in respondents associated significantly with level of exposure to heavy drinker • The QoL domains activity, pain, and discomfort were significantly associated with high level of exposure to heavy drinkers • Older age, low income, low education level, higher levels of own drinking were significantly associated with lower QoL
5. Hussaarts et al. [30] 2012 Netherlands	Examine problem areas that patients with substance use disorders and their family members experience in terms of quality of relations, psychological problems, physical distress, and quality of life. Cross-sectional study European Quality of Life-5 Dimensions (EQ-5D)	*n* = 32 Dyads (persons with substance use disorders s and a family member)) were recruited from a substance abuse treatment program 22 partners Gender of partners: 23% males Mean age of partners: 45 years	Substance use disorder	Not performed	Not controlled for	• No QoL differences between subgroups (patients, partners, or parents) • Poor QoL in family members and in line with heroin addicts
6. Stenton et al. [34] 2014 Australia	Examine challenges to the health and well-being of families of people with alcohol problems A cross-sectional survey incorporating open-ended questions for qualitative analysis	39 Al-Anon members 12 partners Gender of partners: Not reported Mean age of partners: Not reported	Problem drinking	Pearson's product moment for correlation	Not controlled for	Quantitative part: • Higher levels of psychological distress in participants was associated with significantly poorer overall QoL • The participants'

Table 2 Studies examining QoL in partners to persons with substance use problems *(Continued)*

Reference, year, and country	Aim and methods	Sample size and population	Type of substance use in the person with SUP	Test method for associations between having a partner with SUP and own QoL	Controlled for own SUP in PP-SUP in estimations of associations with QoL	QoL perspectives from results section
	and closed-ended questions for quantitative analysis Quantitative part: Quality of life: single question, "How would you rate your quality of life?" Qualitative part: Open-ended questions about the seriousness of impact of their close relative's drinking or substance misuse on their health and well-being					satisfaction with a support group was associated with better overall QoL • QoL in PP-SUP not reported Qualitative part: • Poor relationships and lack of trust • Fear of aggression • Anxiety, sadness, and grief • Financial difficulties/ poverty • Poor communication
7. Cicek et al. [29] 2015 Croatia	Comparing the quality of life (QoL) and family burden in relatives of patients with heroin dependence to healthy controls. A prospective case-control study World Health Organization Quality of Life Assessment-Brief (WHOQOL-BREF)	A total of 50 heroin-dependent patients and 50 of their relatives, and 50 healthy subjects and 50 of their relatives were included in the study Partners: 16% Gender of partners: Not reported, but 50% of total sample relatives were women Mean age of partners: Not reported (but 41 years for total sample of relatives)	Opioid dependence	Pearson product- moment correlation and Spearman's rank correlation	Not controlled for	• No specific partner reports on QoL • QoL significant lower in family members of patients with heroin dependence than controls • All QoL subscale scores negatively correlated with the duration of illness
8. Jiang et al. [33] 2015 Australia	To identify which factors correlate with whether the respondent takes on this caring role for the person in their life whose drinking has most adversely affected them in the current year and to examine how caring for that person impacts the respondent's quality of life and well-being, and use of services Cross-sectional survey European Quality of Life-5 Dimensions (EQ-5D) Personal Well-being Index (PWI)	778 respondents (total survey sample 2649) reported they were harmed because of the drinking of someone they knew (most harmful drinker; MHD). 67 partners Gender of partners: Not reported, but 67% of respondents harmed by MHD were women Mean age of partners: Not reported	Harmful drinking	Not performed	Not controlled for	• No QoL differences (EQ-5D) between subgroups (partners and others) • No significant differences in QoL (EQ-5D) in respondents who care for their 'most harmful drinker' (MHD) and those who did not • No significant differences in QoL between specific categories of MHD relationships • Personal well-being (PWI) significantly worse for people harmed by MHD than people who had no MHD in life • Poorer personal well-being (PWI) for caregivers of MHD in the household than non-caregivers

Table 2 Studies examining QoL in partners to persons with substance use problems *(Continued)*

Reference, year, and country	Aim and methods	Sample size and population	Type of substance use in the person with SUP	Test method for associations between having a partner with SUP and own QoL	Controlled for own SUP in PP-SUP in estimations of associations with QoL	QoL perspectives from results section
9. Nogueira et al. [38] 2015 Spain	To provide new empirical evidence about the effects of alcohol dependence on the health-related QoL of the dependent person and those around them using the general population as the control group Cross-sectional study Short-Form Health Survey-36 (SF-6D)	150 patients with alcohol dependence, 64 family members of patients with alcohol dependence, and 600 persons from the general population 67.7% partners Gender of partners: Not reported Mean age of partners: Not reported	Alcohol dependence	Logistic regressions	Not controlled for	QoL not reported for partners • Significantly lower QoL in family members than in general population (no specific partner reports on QoL) • Reduction in mean utility scores in SF-6D dimensions in family members, particularly in mental health and vitality, with a positive impact from physical function compared to the general population • Age and gender (being a woman) negatively correlated with QoL

QoL measures

The instruments used, QoL domains, and studies are listed in Table 3. A wide range of instruments were used. Five of the studies used instruments covering health-related QoL. Two of these five studies used two different versions of the SF-36: the SF-12 [8] and SF-6D [38]. The SF versions; – 36/– 12/–6D are described both as generic health measures and health related quality of life measures. These instruments cover eight and six domains on mental and physical health, respectively [39–42]. As for the three studies using EQ-5D [30, 33, 37], a QoL measure covering five dimensions of health [43], two of them [33, 37] supplied the Personal Well-being Index PWI [44, 45] to capture measures of life and life satisfaction as a whole. Another study [36] used both the PWI and the Quality of Life Questionnaire (QLQ), which includes eight scales on well-being [46].

The rest of the quantitative studies ($n = 3$) measured QoL using different instruments covering a range of QoL with at least health, social, and relational domains. One study [29] used a Turkish version of the WHOQOL-BREF, which includes eight domains on physical and psychological health and social relations [47]. Some of the instruments covered existential, environmental, and living standard domains. Barber and Gilbertson [35] used Wolcott & Glazer's 12-item well-being scale [48] covering standard of living domains, relational domains, and feelings of self, and including some questions on health. Finally, the study using a single question asking the participants to rate their perceived overall QoL [34] did not report which domains this was meant to cover. They did, however, include a qualitative part with questions about health and well-being, which was supposed to cover QoL.

Population

Only three of the nine included studies [8, 35, 36] were conducted among PP-SUPs exclusively. The six remaining studies [29, 30, 33, 34, 37, 38] were conducted among other close relatives to persons with SUPs, including a percentage of PP-SUPs.

Only four of the nine selected studies provided socio-demographic details of the PP-SUPs regarding age and gender, and three of these five studies also reported on minor children living in the household. In the three studies evaluating PP-SUPs exclusively, the mean age was 42 years [8], 45 years [35], and 37 years [36]. Hussaarts et al. [30] reported a mean age of 45 years in PP-SUPs in the total sample of relatives. The same studies reported the gender of PP-SUPs. There was a large proportion of female partners (average 88%). One study had 77% female partners [30]; in the rest of the studies, the proportion of women ranged from 79% [36] to 95% [35]. Finally, one study [8] was conducted among females only. No studies conducted exclusively among men were found. Five of the remaining studies did not report on socio-demographic variables, such as age and gender, in PP-SUPs specifically [29, 33, 34, 37, 38]. In

Table 3 QoL measures and domains

Instrument	QoL domains	Study
SF-12 (12 items) [39]	Physical functioning Role physical Bodily pain General health Mental health Role emotional Social functioning Vitality	[8]
SF-6D (6 items) [42]	Physical functioning Role limitations Pain Mental health Social functioning Vitality	[38]
EQ-5D (5 items and a VAS on current overall health) [43]	Mobility Self-care Usual activities Pain/discomfort Anxiety/depression	[30, 33, 37]
Personal Well-being Index (PWI) (8 items and a single question of satisfaction with life as a whole) [45]	Standard of living Personal health Achieving in life Personal relationships Personal safety Community connectedness Future security Spirituality/religion	[33, 37]
WHOQOL-BREF (27 items) [18]	Physical Psychological Social relationships Environment	[29]
Quality of Life Questionnaire (QLQ) (192 items) [46]	Material well-being Physical well-being Personal growth Marital relations Parent/child relations Extended family relations Extramarital relations Altruistic behavior	[36]
Wolcott & Glezer's well-being scale (12 items) [48]	Standard of living Relationship Personal feelings of self-worth	[35]
A single question on overall QoL: *How satisfied are you with your life?*	Open-ended questions about the seriousness of the impact of their close relative's drinking or substance misuse on their health and well-being	[34]

addition, when reporting on demographic variables, three of the nine included studies reported that some of the PP-SUPs were parents to minor children living in the household, namely 58% [36], 50% [8], and 54% [30].

How PP-SUPs report their QoL

Three of the nine studies reported QoL exclusively in PP-SUPs [8, 35, 36], but varying QoL results were reported. Only one of the included studies controlled for own SUP in PP-SUPs in estimations of associations with QoL. In this study, a survey investigating the impact of partner alcohol problems in American women [8], lower QoL was found in PP-SUPs than the general population. Lower psychological QoL was significantly associated with higher level of own alcohol use of the participants. The partners' alcohol use appeared however to have at least as great negative effect on QoL in PP-SUPs as the participants' own alcohol use. In another study exploring gender differences in spouses of partners in treatment [36], male partners reported lower QoL than female partners. In addition, the male partners' lower QoL was associated with poor relationships with their children and poor social support skills. The third study examining partners living with a heavy drinker [35] found no associations between PP-SUPs' psychological well-being and negative behavior towards the drinker, regardless of whether such behavior was present when the partner was drunk or sober. The authors underlined that well-being may also be determined by other factors.

The two studies reporting PP-SUPs as part of the overall study [30, 33] also reported on partners' QoL specifically. When examining differences between subgroups, they both found that the PP-SUPs' QoL did not differ significantly from the other subgroups of participants, such as SUP patients or other relatives [30, 33] . These studies also presented various results regarding QoL. Both studies [30, 33] found that the relatives [30, 33], including PP-SUPs, reported significantly lower QoL than the general population. The authors [30, 33] proposed that the poor QoL may have been due to the strains and burdens of living with or caring for a person with a SUP. Further, when examining factors associated with QoL, both studies [30, 33] found that poor QoL in relatives [30, 33] is associated with the severity of the substance use in the person with SUPs. Jiang et al. [33] also found that caring for the person with alcohol use is negatively associated with QoL.

The results of the last four studies [29, 34, 37, 38] did not differ between subgroups, but reported on relatives of people with SUP as a whole, though they reported a percentage of PP-SUPs in their results. All of these studies found poorer QoL in relatives of people with SUP than in the general population or controls, with various factors that may explain this difference. In a population survey examining the negative impact of exposure to others' drinking, Casswell et al. [37] found a reduction of QoL that was significantly related to an increase in the level of such exposure, and that 75% of the participants represented in the group reporting highest exposure were PP-SUPs. They also found a strong association between higher QoL and being a woman, though being unemployed/sick and on low income was associated with lower levels of QoL for all participants. In the estimations of associations with QoL in the participants, one of the studies found that higher levels of the relatives' (including PP-SUPs) own drinking were significantly associated with lower QoL [37]. The other study [34] found no significant associations between the relatives' (including PP-SUPs) own substance use and measures of QoL. In a study of 150 alcohol-dependent persons and 64 family members of alcoholics, Nogueira et al. [38] found that poor QoL in family members was generally associated with higher age and being a woman, whereas education and living with a partner positively correlated with QoL.

The remaining studies including relatives [29, 34] in general reported a negative correlation between low QoL in relatives and duration of heroin dependence, age, and education of both patients and relatives, and the onset age of heroin use. Stenton et al. [34] found that poor QoL in relatives was associated with psychological distress, whereas better QoL was associated with the level of satisfaction with attendance in a mutual aid support group. In this study they found no significant associations between relatives' (own) alcohol consumption and measures of QoL or well-being.

Discussion

The studies included in this scoping review originated from a wide range of countries, and the majority were conducted after 2010, which indicates an increased interest in research focusing on both QoL and PP-SUPs. One study with a mixed methods design [34] was included and no qualitative studies matched our inclusion criteria of exploring PP-SUP experiences with QoL were found in the research emerging after 2010. The majority of the studies used established and generic instruments when examining QoL. However, these instruments are based on different concepts and theoretical perspectives of QoL; therefore, findings cannot be consistently compared across studies. Many studies also utilised different comparison groups (e.g. the general population, people who had no person with SUP in their life, controls, patients vs. partners, vs. parents, etc.), which shows a heterogeneity between studies.

As for the instruments used to measure QoL, two of the studies that used the EQ-5D, a QoL instrument solely covering health domains, added the PWI with broader domains [33, 37]. Three other studies using EQ-5D [30], SF-12 [8], and SF-6 [38], did not include other instruments to add additional dimensions other than health when reporting on QoL. As health-related QoL measures often refer to an illness and treatment of patients [23], and tend to be more "objective" as they target specific functioning levels, they may have been considered suitable when examining health-related QoL in persons with SUPs. The question remains whether this reflects the QoL dimensions that are most important to family members or relatives in general or PP-SUPs specifically; these persons may experience a difficult life situation but are not necessarily ill. The remaining four quantitative studies [11, 29, 35, 36] used instruments covering a wider range of QoL domains in addition to health. This included at least social and/or relational domains, and some of them even existential or environmental domains. Conclusively, though all the instruments covered the health domain, only half of the studies made use of instruments that embrace QoL in a broader manner, including at least social and relational dimensions. Therefore, the findings are heterogeneous because researchers are not consistently using the same measures. Many studies only include particular dimensions of QoL rather than a more comprehensive concept of QoL. The mixed methods study [34], which included an overall question about quality of life, introduced a broader perspective on QoL by including a single qualitative question about the participant's well-being in different areas. This qualitative information can provide further contextual information and explanations for quantitative findings and may be useful to include in future research on QoL.

For future research of PP-SUPs, QoL measures that capture the broader dimensions of QoL are recommended. In addition, generic instruments that provide the possibility of cross-population comparisons would be useful. It also seems that multi-dimensional QoL forms could better capture variations in the life situation of these partners and provide a more holistic understanding of their overall life situation's impact on their QoL. Of the instruments included in the studies in this review, only WHOQOL-BREF include social, relational, and existential dimensions in addition to physical and mental health. To capture more dimensions than those covered by the highly health-specific instruments (e.g., EQ-5D, SF-6D, and SF-12), they can be used together with PWI, which also includes social, relational, and existential dimensions.

Only three of the included studies focused on PP-SUPs exclusively. However, two of the other studies including PP-SUPs as a subgroup did report on their QoL. The remaining studies did not differ between subgroups when presenting QoL results, but presented the QoL results to apply to the entire sample. Thus, more research is needed that focuses on PP-SUPs exclusively. In the case of socio-demographic variables, the average age of PP-SUPs is relatively low (42 years), which may reflect the fact that in three of the nine reviewed studies over half of the participants were described as caring for minor children. Parenting was however not themed specifically, which indicates a knowledge gap. Women comprised more than 3/4 of the participants on average. This is in line with other research conducted among PP-SUPs in which the proportion of women has often been higher [13, 14, 49]. Though the findings by Dawson et al. [8] represent female partners only, and the rest of the studies reported a majority of female PP-SUPs, no studies were found that focus exclusively on male PP-SUPs. Therefore, there is a gap in knowledge on the QoL of male partners, especially as male partners have reported very poor QoL [36], and further research on male partners' QoL is needed.

A key finding was that, in the majority of the studies, substance use by the person with SUPs was the factor that related most to poor QoL among the participants, including PP-SUPs [8, 30, 33, 35]. An association was found between severity of SUPs and poorer QoL in PP-SUPs [30, 33, 37]. The majority of studies also reported that the participants, including PP-SUPs, described a lower QoL than the general population. These findings indicate that substance use itself has a great impact on the PP-SUPs' QoL. One study found that PP-SUPs' QoL was more affected by SUPs in a partner than the PP-SUPs' own substance use [8]. In addition, several of the studies showed that PP-SUPs had equally poor QoL as people with SUPs. This indicates a very stressful life situation. Although they are not by definition ill, long-term and serious substance use problems have a major impact on PP-SUPs' QoL. Using a broad measure of QoL that includes at least health, social, and relational dimensions, rather than pure health-specific QoL measures, in future research could be more suitable for capturing partners' life situations.

The results describing associations with QoL varied greatly. In addition to the impact of SUPs on QoL, there are some specific findings that need to be discussed and addressed with respect to PP-SUPs. Firstly, only one of the studies controlled for PP-SUPs' own substance use in their estimations of associations between having a partner with SUP and lower QoL. This study found a significant association between lower QoL in PP-SUPs and own substance use. Two other studies, conducted among relatives such as people exposed to heavy drinkers [37] and family members of people with alcohol problems [34], respectively, also examined associations between the relatives' own substance use and QoL, but did not report on PP-SUPs exclusively. One of these studies [37] found that substance use in the participants was associated with QoL. Hence, we cannot know how the PP-SUP's own substance use, and their partners' substance use, respectively, impact on partners' QoL. It is interesting however to see that male PP-SUPs have lower QOL (than female PP-SUPs) in a study that does not control for own consumption [36], whereas female PP-SUPs have lower QOL (than the general population) in the study that does control for own consumption [8]. This indicates that own consumption may be an important confounder to control for. Controlling for own substance use may be particularly important for disentangling gender differences in associations between being a PP-SUP and QoL. This result represents a gap which needs to be further examined in future research. Secondly, the fact that three of the studies [8, 30, 36] reported on whether the partners had minor children living in the household must be considered when presenting the associations with QoL. This is especially important when poor QoL was found to be associated with being male and poor parent/child relations [36]. Several studies have shown that the parent/child relationship is disrupted due to SUPs in a parent [2, 12, 50]. The PP-SUPs' poor QoL may influence the capacity to fill the parenting role. Taken together, these findings underline the importance of paying attention to PP-SUPs that also have a parenting role. Possible negative outcomes for partners is relevant not only to tailor support for their own sake, but also to enhance parenting and prevent negative outcomes for the children. Conversely, better parenting ability may mutually reinforce the parent's overall situation [51].

As for PP-SUPs' positive associations with QoL, one study conducted in 1997 found that positive behavior towards their partner with SUPs was associated to some degree with PP-SUPs' QoL [35]. Though these are also important findings to address clinically, a minority of studies seem to have examined other factors associated with QoL in PP-SUPs, both positive and negative. Studies reporting on PP-SUPs' positive associations with QoL seem limited, and there is a gap in knowledge in this area. Studies investigating and exploring QoL qualitatively and quantitatively in PP-SUPs are also needed.

Conclusions

This scoping review shows that poor QoL of PP-SUPs is associated with the partner's SUP, and this should be addressed by health personnel who need to increase focus on PP-SUPs' QoL when patients with such problems are in treatment. This result is also relevant for policymakers. PP-SUPs should be included in the development of national guidelines based on larger scale research. The importance of national guidelines being evidence-based is emphasized; therefore, such evidence must be valid and reliable. Currently, the evidence is ambiguous, and there is a need for larger generalizable studies. Furthermore, there is a need for more research among PP-SUPs who also are parents to minor children as poor QoL may affect parenting. Gender issues should also be taken into consideration when conducting such studies.

This review has revealed some important gaps with respect to knowledge about QoL in PP-SUPs. First, due to the minority of studies conducted among PP-SUPs exclusively, there is a need for further research examining QoL in this group. QoL has been studied in PP-SUPs to a limited extent. In addition, a variety of QoL instruments with various dimensions of the concept included have been used in studies of this particular population. This indicates a challenge in making comparisons between groups. On the one hand, generic instruments that may compare this population with the general population or other at-risk-groups exist, whereas on the other hand, generic instruments may fail to capture specific areas of importance to certain populations, such as PP-SUPs. Thus, in addition to studies with larger scaled quantitative designs, a need exists for research exploring QoL qualitatively in this particular group, especially among PP-SUPs who also have a parenting role.

Strengths and limitations

The main strength of the present scoping review is the comprehensive database search without a date limit. The search was conducted with comprehensive search terms, which identified a large number of studies. This strength is largely due to close collaboration with two highly experienced academic librarians from different disciplines during the search. The titles and abstracts were screened thoroughly and systematically performed by two authors. Full-text studies were further screened by four authors, followed by reference lists and discussion meetings, which also assured against a loss of relevant studies. However, studies in languages other than English were not included, which may have caused some relevant records to be missed. Though the search was performed in six databases, this number is not exhaustive. However, the selected databases and the search performed were advised by experienced academic librarians in order to cast as wide a net as possible regarding the population, concept, and context.

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Availability of data and materials

Data sharing not applicable to this article as no datasets were generated or analysed.

Authors' contributions

BB and BW designed the study and the literature search strategy, in corporation with librarians. BB undertook data cleaning, and BB and BW performed title and abstract screening. BB, BW, ASS and MMH undertook full paper assessment. BB, KF, and BW performed the data extraction and analysis of all data, with input from ASS, MMH and TR as required. BB and BW drafted and revised the paper, followed by a critical revision from KF, TR, ASS and MMH. All authors gave final approval of the manuscript and are accountable for all aspects of the accuracy and integrity of the work.

Ethics approval and consent to participate

Ethical approval was not required for this study.

Consent for publication

The paper does not contain any personal data.

Competing interests

The authors declare that they have no competing interests.

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Paper 3

“It’s like being stuck on an unsafe and unpredictable rollercoaster” — experiencing substance use problems in a partner

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Abstract

Living with a partner with substance abuse problems may induce strains in an individual’s everyday life, including poor health, disrupted family life, and social isolation; this may lead to dropping out of education or work, a lack of safety and support, and facing various dilemmas. The purpose of this study was to describe and explore these partners’ everyday experiences, including their parental roles. Qualitative interviews were carried out with ten partners and ex-partners, and thematic analysis was used to organize participants' experiences. The findings demonstrated that sharing life, including parenthood, with a partner with substance use problems affected every aspect of the participants' lives, and entailed being dependent on their partner's ups and downs. The overall theme, "being stuck on an unsafe and unpredictable rollercoaster," is explored through three main themes: "relational strains," "stigma, shame, and lack of support," and "searching for hope and meaning." As a result of the negative impact of their circumstances on their everyday lives, these individuals need support to handle the challenges that they face, but find it difficult to ask for help out of fear of stigma. Peer support groups seem to be essential in enabling them to find ways out of their situation.

Keywords: substance use problems, partner, parenting, peer support, everyday life, qualitative

Introduction

"It really turns your entire life upside down (…) you are faced with impossible situations; it is really so unnatural and irrational that it is difficult for a normal person to relate to it in a rational way. (…) So it's like living in a war zone, in a way." (Kate, ex-partner)

The above quotation reflects one experience of being a partner to someone with substance use problems from this qualitative Norwegian study.

Substance use problems (SUP) in a family member negatively impact the whole family (Velleman, 1992, Bancroft et al., 2002, Hjärn et al., 2014). An estimated 100 million adult family members worldwide are affected by SUP, and are at risk of developing their own health problems as a result of their experiences of related strains and stresses (Orford et al., 2013). Examples of such stresses include disturbed interactions within the relationship (Mitchell and Burgess, 2009), aggression and violence (Orford et al., 2013, Dawson et al., 2007), the risk of social isolation (Orford et al., 2010b, Arcidiacono et al., 2009), and the fear of being stigmatized (Walter et al., 2017, Arcidiacono et al., 2009), but also difficulties in managing one's own emotions in combination with hopes of changing the situation back to "normal" (Orford et al., 2013).

One particularly relevant group of adult family members consists of partners to individuals with SUP. A recent scoping review (Anonymous, 2018) found that this group experiences significantly lower quality of life (QoL) than the general population, and that their QoL is negatively associated with SUP in their partner. When these partners also share parenting of minor children with the person who has SUP, this may present particular challenges to them: it has been pointed out that parental SUP are associated with disruption of rituals and routines and with changes in roles and responsibilities; in addition, resources may be allocated to the person with SUP, at the expense of other family members (Haugland, 2005; Mitchell & Burgess, 2009).

Although formal and informal social support is important for these relatives (Orford et al., 2010a), the practice of providing such support seems to be limited in its focus to clinical settings (Selbekk and Sagvaag, 2016). A deeper understanding of how these partners may experience everyday life, including parenting, would represent important knowledge for practitioners in health and social services to enable them to support such individuals in connection with the treatment and follow-up of their partners with SUP.

There is also a need for studies of the experiences of partners of individuals with SUP through a broader lens than one based on a preconception that the reason they remain in dysfunctional relationships is personal pathology; rather, such individuals should be viewed as normal human beings who have been exposed to a number of serious and stressful life events (Orford et al., 2013a). A review from 2002 (Bancroft et al., 2002), which still seems relevant, concluded that more studies were needed with partners who did not have their own SUP. Such studies should focus on the views and roles of these partners. Qualitative exploration of how partners of individuals with SUP experience their everyday life and parenting role could contribute to an improved understanding of their situation.

Aim and research question

The aim of this study was to describe and explore the everyday experiences of partners of individuals with substance use problems, with the research question: how do partners of individuals with substance use problems describe their everyday experiences, including their parental role?

Methods

Design

A qualitative, descriptive, and explorative design was employed to explore the research question. We considered such a design appropriate as a method of obtaining a fuller understanding of the everyday experiences of the partners of individuals with SUP in relation to SUP in their significant other. A semi-structured interview guide with open-ended questions was developed in collaboration with the organizations A-Larm and *Landsforbundet Mot Stoffmisbruk* (LMS; in English: the National Association Against Drug Abuse).

Recruitment and participants

Participants were recruited through the organizations A-Larm and LMS. The inclusion criteria were: (1) partners or ex-partners of individuals with SUP (relating to alcohol and/or drugs); (2) who shared parenthood with this partner or ex-partner, and (3) who had experience of caring for minor children at the time of the SUP in the other parent.

All participants met the inclusion criteria. Altogether, ten partners participated: six were women and four were men. Their ages ranged from 35 to 66 years. Two participants shared experiences from the time when their partners did have SUP, although their partners were non-users at the time of the interviews. These two participants still lived with their respective partners. The remaining eight participants were ex-partners, of whom four reported current SUP in their co-parent. Seven of the participants were parents to minor children at the time of the interviews. One was a student, two were employed (full time, of whom one was on sick leave), four received a full disability pension and one had applied for such a pension, one received a combination of disability pension and income from employment, and one did not share their employment information. None of the participants reported having SUP themselves.

Data collection

Individual qualitative interviews were conducted, covering overall themes relating to the participants' everyday experiences as partners of individuals with SUP, revolving around their experiences of being a close relative of someone with SUP, their roles, support needed and received, and possible positive outcomes of their experiences. The same questions were used in all interviews, but the order of questions could vary depending on how each participant addressed the different themes. At the end of each interview, the participant was given an opportunity to share any reflections that had not already come to light. Each interview lasted approximately 60 minutes and was carried out in the participant's preferred location (usually at the participant's home) during the period from April 1 to September 30, 2014. The interviews were transcribed verbatim.

Analysis

We conducted an inductive, thematic analysis of the data, inspired by Braun and Clarke (Braun and Clarke, 2006), in order to extract and thematize the participants' everyday experiences, including experiences of parenting, while having a partner with SUP. The interview transcripts were read several times, and notes were taken on possible meaning units, with suggestions for coding words (Brinkmann and Kvale, 2015). The authors met and discussed these notes thoroughly several times, referring to the interview texts when in doubt, in order to develop meaning units, sub-themes, and themes.

In the process of organizing the data, we clustered the sub-themes in accordance with their content, and identified preliminary themes. These sub-themes and preliminary themes were thoroughly discussed, with cross-references made between the interview transcripts and proposed themes. Several sub-themes were re-arranged, with content being moved to another sub-theme, or changes made to the names of codes or sub-themes. The themes were scrutinized and re-organized several times before we reached agreement that the data should be organized into three themes, each with associated sub-themes.

Ethics

The study was financed by the Norwegian Health Directorate. Participants gave written informed consent prior to their participation. Data were anonymized in the transcription process, and pseudonyms are used in the quotations presented in this paper. The study was approved by the Regional Committees for Medical and Health Research Ethics as a sub-study of the project with reference no. 2012/1176.

Results

Overall, the results showed that sharing life with a partner with substance use problems meant that their partner's problems became the participants' center of gravity, affecting every part of their lives. Through our analysis, three main themes emerged: "relational strains," "stigma, shame, and lack of support," and "searching for hope and meaning" (Table 1). The participants emphasized that they often felt unsafe, and that the unpredictability of the situation was burdensome but difficult to escape. To be close to someone with SUP meant being dependent on their ups and downs. We thus named the overall theme: "Being stuck on an unsafe and unpredictable rollercoaster." Further descriptions and explorations of each of the three themes are presented through the sub-themes. The close interconnections between the themes should be taken into consideration.

Please insert Table 1 about here

Relational strains

This theme revolved around the participants' everyday experiences of strains induced by their relationship with a partner with SUP. In this section, we describe the sub-themes: altered roles and relationships, dilemmas, lack of safety and security, and health at risk.

Altered roles and relationships

The participants described how their familial roles were altered; they typically felt increasingly alone and lonely, while taking on the overall family responsibilities. This meant that they had no one with whom to share worries or make decisions, from minor everyday decisions to overwhelming issues, such as worries about whether their partner was alive or not following an overdose. The sense of sole responsibility particularly affected their parenting role: instead of having a partner as a co-parent, they sometimes had to protect their children from emotional or physical danger imposed by the other parent.

The feeling of being responsible for the well-being of all family members was described in terms of being a kind of "protector," which included feeling torn by the need to balance a variety of needs. Milly (an ex-partner) noted: "*Mostly it was about concealing that ... they were addicted… to make it possible to keep the peace in the house. Step gently; know when not to keep quiet, always be on guard."* Participants endeavored to protect their children from experiences including threats or violence, worrying about their parent, disappointment, and experience of their parent being under the influence: *"My eldest son recalls … [that he] went home to his father and then his father was so high that he didn't recognize him. He won't forget that"* (Eve, ex-partner). They could also take on the role of protecting their partner: *"... I thought I was protecting her, so I helped her get pills at first […], because I believed that she needed them, at least occasionally"* (Lawrence, partner). Having a protecting role was challenging when participants felt that they had to set boundaries with the other parent, since this could greatly upset him or her. At the same time, participants felt bad if they did not do anything: "*Actually, I just left it… just floating away, instead of making trouble. It's certainly terribly wrong, but…"* (Lawrence, partner).

Their altered role also tended to influence participants' relationships with their partners: emotionally, practically, and socially. Furthermore, a common experience among the participants was that their own well-being was closely related to the consequences of the SUP: they could feel better when their partner's substance use decreased; however, they were not without fear of relapse, and felt worse when it increased.

Descriptions of the altered relationship included feelings of slowly losing confidence in their partner's ability and willingness to be a partner and parent. Gerry (ex-partner) explained how he experienced his wife's trust-breaking behavior: "*It was like hell, basically. […] That feeling you have after all, for someone you've been with for such long time, and you can see that she's not 'with it' at all; this isn't at all the person you know, with the drinking… At that time, she had a visit from another man to the cabin at night… And you know she's totally erratic in what she's doing, and doesn't know what she's doing."*

As a result of the negative consequences of the partner's SUP, a major issue was how to make the substance use stop. When their efforts did not lead to any changes, participants experienced a huge strain. "*It was a blow when I finally knew… that whatever I did, it wouldn't help him to quit anyway, which was probably something I tried as much as possible. [...] I don't remember [...] how many times he relapsed, [...] before I [...] started thinking that if I do this and that, maybe he won't do it anymore (laughing)"* (Eve, ex-partner).

Dilemmas

The participants described periodically facing overwhelming dilemmas, particularly when they were feeling alone in decision-making. One dilemma lay in balancing their children's need to understand the situation with the desire to protect them from knowing too much, e.g., as Toni (ex-partner) explained: *"I tried to cover up for them how bad it really was."* This dilemma included the challenge of containing the children's feelings, as this example shows: "*She was very defensive. 'You're not allowed to talk badly about Dad' — because [...] she perceived him as the weak one [...]. With me, she argued forcefully, while he was sacred [...]. So it was better for us never too talk about dad, at all"* (Kate, ex-partner).

Some participants experienced a feeling of walking a tightrope regarding how to talk with their partner. They could try to be supportive when their partner seemed to have problems. However, acting as a kind of psychological support could end in conflict, as Hector (partner) explained: “*I immediately realized that she needed someone else to talk to. For us, and her parents, there are too many feelings, and frustrations, and anger, and disappointments, [it’s] simply too hard to talk about ….”*

Those participants who were ex-partners experienced additional strains relating to visitations between their children and the parent with SUP. Several participants mentioned that their ex-partner could be a good parent when clean and sober, which made it challenging to decide in advance whether a meeting should take place. One dilemma was whether regular visitations would help their ex-partner to recover, and at what cost this would be for the children. To deny such meetings might lead to threats, as well as a loss of contact with the other parent’s extended family — people who might be or become providers of essential support to the children. Another example was the fear of potential unpleasant or dangerous situations that might occur during visitations. Eve (ex-partner) explained: *"I feared someone would pick him up and offer him something, I was afraid that there might be drug debts ... I didn’t want my son to meet anybody there."* To safeguard their children emotionally and physically, the participants thus had to be alert before, during, and after such meetings.

Furthermore, it was demanding to handle their children’s disappointment when the other parent did not appear for scheduled meetings or appeared under the influence of drugs. *"He remembers that dad didn’t show up. [...] ‘You can’t be with the kids.’ And he says ‘I'm not high’* *(laughs bluntly) [...] And then, to be consistent and say that you, you are high! And the kids: 'Yes, but dad said he wasn't.' 'Yes, but mom sees it.' That's been difficult, [...] that they couldn't see it the same way"* (Eve, ex-partner).

Lack of safety and security

A huge strain on the participants was caused by the negative consequences of the SUP on their family's safety and security. This included experiences of being manipulated, harassed, and exposed to conflict, threats, and violence by their partner, as well as the unpredictability of their substance use (how much, how dangerous, what kind of behavioral changes would ensue?). This became a huge cost of the relationship, leading to a feeling of insecurity or being unsafe. The participants might also experience a lack of trust in their own judgements. Typically, the parent with the SUP argued that it was their partner who was exaggerating the situation. The following illustrates a reflection by Kate (ex-partner): *"…it was like living in a nightmare ... I was somehow manipulated enormously... one thing was said, but [it was] done differently."*

Being subjected to threats and violence was described as detrimental to both the children and the participants themselves. Some were also exposed to physical violence, sometimes in front of the children. This could be sufficiently severe that they feared for their life. In addition, there were threats by the partner of suicide, which contributed to the lack of control and predictability. Milly (ex-partner) described how she had to be very conscious not to push too hard: *"...[there was] very much fear of crossing the line; fear of suicide threats from my ex-husband … [or] that he would kill me."*

Health at risk

The totality of strains was described as linked to the creation of a vulnerable health status, manifested in bodily stresses and pains, weight loss, and various emotional or mental difficulties such as sleep disturbances, concentration problems, depression, and anxiety. The following quote describes the experience of Grant (ex-partner): *"And I've been the one who had to drive, bring, pick up ... Like having such an overloaded role all the time. One year ago, I had a real breakdown."*

Their partner's SUP became a never-ending worry, inducing fear, grief, and stresses regarding the possible impact on the children. Some participants worried about developing their own SUP. Grief could be manifested in various ways: this could relate to the lost possibilities of fulfilling their own and their children's expectations about life, or to the negative development of their partner's life. A stressful factor was that the participants' overall responsibility meant that they always had to be present to safeguard the children. One way to survive the situation was described in terms like *"unplug everything, it's too brutal"* and *"sweep it all under the carpet."*

Stigma, shame, and lack of support

This theme described how the participants experienced the SUP's effects on them with regard to the sub-themes: impacts on oneself, children, and social life, and lack of support.

Impact on oneself, children, and social life

Stigma and shame affected how the participants viewed themselves, their children, and their (lack of a) social life. A common fear was that others would discover the SUP, and if so, how the associated stigma would affect their family members. The shame or guilt that they felt was threefold: in relation to the substance misuse and their partner’s conduct; in relation to not being able to help or feeling that the SUP was in fact their fault; and for not leaving when the SUP affected their children. Efforts were made to conceal the situation at first, which at a certain point became impossible. A different approach was to be open about the problem, which for some became possible through peer support.

The participants’ experiences of stigma and shame could lead to a lack of a social life. If their partners behaved in an unpleasant manner, participants tried to avoid social settings. Another reason to avoid social contact was the difficult feelings arising from meeting others who seemed to be successful in life. Those who had found peer support groups reported that this made a huge impression on them and difference to them, in particular with regard to no longer being alone and lonely.

Lack of support

The feeling of a lack of support was mostly described in relation to health services, but a lack of support from family and friends was also part of the theme.

All the participants described a lack of sufficient treatment and follow-up of their partner, and a lack of support for themselves, from health services. When they felt excluded from their partner’s treatment plan, this induced a series of worries, such as: has my partner actually been admitted? how is he or she doing? when and in what state will he or she be discharged? However, when they did receive such information, admission of the other parent to hospital could represent a safe respite to them, albeit not one without uncertainties; voluntary admissions could feel unsafe, since their partner might decide to discharge him- or herself at any time.

“[...] on Saturday she was hospitalized after an overdose ... I talked to them on the phone [...]. I said that ‘you must hold her as long as possible, I've struggled for so long and I can’t take it anymore. If she’s discharged now, I might collapse, and then what about the kids?’ The answer was ‘we can’t lock someone up because you are tired.’” (Gerry, ex-partner).

Given that a common approach was to conceal the SUP from others, asking for support could feel paradoxical. However, several of the participants mentioned that peer support groups had made them realize that they needed support, and that they should not be afraid of talking about the situation. For some, such openness had led to obtaining support from their families and networks.

Searching for hope and meaning

This theme described participants’ journeys in terms of the sub-themes: from hope of change to loss of hope; re-establishing hope, gaining new meaning; and still feeling vulnerable.

From hope of change to loss of hope

The participants reported that their partner’s SUP influenced their entire situation and being. They thus used all available resources to attempt to make their partner stop the substance abuse. They tried threatening to leave, begging and being quiet and kind, or hoping for the best when positive things happened. Milly (ex-partner) explained how she had repeatedly threatened to leave: *"And then I said, ‘I can’t take it anymore, I’m leaving.’ And he says: ‘yes, but then I’ll take a nap.’ That’s when I thought: I've said this many times before.”* Eve (ex-partner) shared her hope of a change: *"When I discovered I was pregnant, I thought — now, now, now it will stop, he will stop now, when I’m having a second child."*

The participants described the years of trying without achieving any change as a process of “ups and downs,” with a never-ending fear of relapse. Some expressed this as a feeling of no longer having a life. They slowly lost hope that a change would occur, and reached a kind of “rock bottom” or a point of no return. *“The last straw was when he started buying* [drugs] *on the street ... and I got it confirmed, and he denied it — then I left. Since I then saw that it doesn’t matter what I do”* (Milly, ex-partner).

Re-establishing hope, gaining new meaning

Many of the participants described in retrospect how they only were able to re-establish hope, find meaning, and learn from their experiences after reaching this point of no return. An essential component of doing so was to obtain some distance from the SUP, either through the recovery of their partner, or by ending the relationship. Kate (ex-partner) explained: *"Even if he had turned on his heel and said yes, I'm going to change; I’ll admit myself for treatment […], I still don’t think it would be of any use […] with everything that happened and the way he’d been. Because it was simply really completely unforgivable."*

The informants also reflected on how such a turning point had helped lead to a positive change in how they understood themselves and the situation. Eventually, this process also made them aware of how much space their situation had occupied in their thoughts and feelings. Reconciliation was one part of the process of acquiring new hope, which was described as necessitating great efforts to achieve.

In regard to finding meaning in what they had been through, participants emphasized that they had gained new insight into themselves and found that they had more strength than they used to believe. They had also gained a better understanding of other people through the lessons they had learned.

Still feeling vulnerable

Despite having reached a point in life where they were able to reflect on a very challenging period, the participants still felt weak and vulnerable, although they seemed strong from the outside. Even after ending their relationship with their partner, their worries and strains continued, since they were still co-parents. It was still hard work to make sure that their children were safe and felt happy. This was particularly an issue in cases in which the other parent still misused substances. "*It's still a struggle and it hurts her, and I see that we are relatives, and will keep on being that, at least for as long as he lives, or we live — or whatever happens. So, the problem is there, it's not something that's killed off or disappears … I make as good a life as I can for her, but it's come at a great cost*" (Kate, ex-partner).

Another aspect of this vulnerability was how the participants felt, physically and emotionally. Although some were now in a place where the SUP had improved in one way or another, some still had health issues and problems staying in work. "*I'm still really down. If only I could feel a bit of joy again. [...] There's something missing in life. Even if you have everything you need, but what you need is that joy. The wish to do things ... yes, just to take your son out because you want a walk in the forest, that's a giant threshold*" (Gerry, ex-partner).

Even from a position of having ended the relationship, or one in which their partner's SUP had ended, participants questioned whether they would ever feel safe or trusting again, even when enjoying life or experiencing things having fallen into place. Staying in the relationship meant that a relapse would have tremendous negative consequences; having ended the relationship still meant that the family was exposed to the risk of strains, stresses, and burdens.

Discussion

Overall, the results showed that the experience of partners of individuals with SUP was that their everyday life depended on the state of their partner's SUP. Their own needs, such as health care, a social life, and safety, were less attended to. It was challenging to be the sole adult taking on the overall familial responsibilities, particularly in the case of parenting responsibilities. Hopelessness emerged as the participants experienced repeated relapses and witnessed conduct that induced distrust in their partner. These findings are in line with the experiences described by relatives in general of individuals with SUP; strategies to deal with the situation may include restraining oneself, providing uncritical support, or resigning oneself to the situation, and thus accommodating the person's SUP (Orford et al., 2013), as well as experiencing worries, anxiety, depression (Orford et al., 1998, Orford et al., 2001), uncertainty (Orford et al., 2010b), social and/or relational struggles, and hopelessness (Arcidiacono et al., 2009, Orford et al., 2013). Studies of relatives' QoL when a family member suffers from SUP have found that a poor relationship with the family member with SUP is tied to poor health in the relative, and this often includes giving up social activities (Orford et al., 2013, Anonymous, 2015).

As with SUP in our study, addiction in a partner has previously been shown to become the "center of gravity" in families with a member with gambling problems (Borch, 2012). This indicates that addiction issues are overwhelming and consuming for family members. Our findings showed that the participants' lack of safety and security was linked to relational strains with their partner with SUP, such as exposure to manipulation, aggression, and violence, sometimes witnessed by their children. Chermack et al. (2008) observed high levels of psychological (77%) and physical aggression (54%) and violence (33%) in situations involving a partner with substance use problems. Protecting children from such experiences is crucial.

Courtesy stigma (Goffman, 1963) or stigma by association (Mehta and Farina, 1988) means that, for example, the family members of people with SUP are exposed to stigma, and also to self-stigma (Mak and Cheung, 2008). People with substance use problems are highly stigmatized in society, which leads families to conceal the problem in order to avoid social exclusion (Marshall, 2013), in line with the findings of our study. The importance of social support in such situations, however, is emphasized in the literature (Arcidiacono et al., 2009, Orford et al., 2013, Naylor and Lee, 2011). Relatives' experiences of barriers to acquiring such support should be acknowledged (Orford et al., 2013).

This study shows that partners' needs to protect themselves, their children, and their partner induced several dilemmas. Such dilemmas have previously been shown to put further strain on relatives (Anonymous et al., 2013), including relatives of individuals with SUP (Orford et al., 2013). In the present study, participants' approaches to managing these dilemmas included avoiding social settings, keeping quiet to avoid family conflict, threats, and violence, and finding ways to safeguard their children. Osborne and Berger (2009) found that parental substance abuse puts children at risk for negative health and behavioral outcomes. Prioritizing the children could mean doing so at the expense of the partner with SUP, which illustrates one dilemma faced by participants. One way out could be to keep one's distance from the other parent. Research has pointed out that partners of individuals with SUP may keep their distance in this way in order to fulfill their parental role on a daily basis (Naylor and Lee, 2011, Haugland, 2005, Arcidiacono et al., 2009, Mitchell and Burgess, 2009). As in the case of the dilemmas reported in our study, other studies have shown that while safeguarding their children, partners are also very supportive of their family member with SUP, and try to keep household matters in order, such as housekeeping, finances, and other family-related tasks (Mitchell and Burgess, 2009, Naylor and Lee, 2011).

When trying to orient themselves toward the future, all of the participants described reaching a "point of no return," which implied recognition that they could not change the situation, either by trying to make their partner stop using substances or by staying in the situation. The impact on several areas of relatives' lives caused by making efforts to induce change with limited success has also been described in other studies (Orford et al., 1998, Orford et al., 2013).

At this point, the participants had reached "rock bottom," which for the majority meant that they had to distance themselves from the SUP. Some experienced this as a "turning point," which has been described as an opportunity to overcome disadvantages in life (Sampson and Laub, 1996). Although our study shows that participants described a turning point based on a kind of "rock bottom," this did not happen without a prior process in which hope turned into hopelessness. Reaching an awareness of necessary change has been described as a "catalyst for change," often triggered by one or more critical life events (Naylor and Lee, 2011).

Many of the participants experienced a change in their situation after acquiring some distance from the SUP, either through their partner's recovery, or by leaving him or her. In retrospect, many of the participants reported that this process of change led them to find new meaning in life. Peer support groups were highlighted as essential in this regard. Naylor and Lee (2011) found that partners must acquire an increased capacity for self-reflection in order to foster a better focus on themselves. Our study showed that the acquisition of some distance from the SUP seemed to be essential in improving participants' capacity for self-reflection.

Although most of the participants described experiencing improvement in their everyday life after having distanced themselves in one way or another from the SUP, they still felt vulnerable. This finding indicates that they would take a long time to heal from their experiences as relatives. Their ongoing worries about relapse were strongly related to concerns for their children and concerns that such an event would again imply strains, stresses, burdens, and a lack of safety and security, both for their children and for themselves. This seems to support the fact that relatives' descriptions of their greatest worries for the future relate to issues concerning their children, but also the view that a degree of withdrawal (from SUP) and gaining one's independence remains important in coping with the situation (Orford et al., 2013).

Strengths and limitations

The participants covered a range of topics relevant to the aim of the study. Six to 10 participants is considered sufficient to observe relevant patterns in exploratory studies (Malterud et al., 2016). However, given the limited number of participants, the findings cannot be generalized.

The participants were recruited from relatives’ associations (in some cases, on an occasion on which their partner was admitted for treatment), which may have implications for the transferability of the findings. However, the participants’ reflections came from years of experience, including periods during which there were exceptions to the above-mentioned circumstances. By following Guba’s (1981) four principles to ensure trustworthiness, the findings of the present study may be transferable to populations or contexts similar to those of this study: namely, the everyday experiences of partners of individuals with SUP. We used open-ended questions and provided sufficient time to respond in order to invite the participants to share additional reflections in the interviews; this strengthens credibility. By describing both the data collection and analysis procedures, we ensured transferability. Confirmability was pursued by presenting and discussing preconceived notions about the data within the research team, and comparing our results with those of relevant, peer-reviewed studies. Dependability was strengthened by using the same semi-structured interview guide in all interviews.

Conclusion

As a result of the overwhelming negative impact of their circumstances on their everyday lives, the partners of people with substance abuse problems need support to handle the massive strains and dilemmas that they face, but find it difficult to ask for help out of fear of stigma. Peer support groups seem to be essential to enable such individuals to find ways out of their situation.

Implications for practice and further research

Health services should include partners in the treatment and follow-up of individuals with SUP, particularly when they share parenthood of children, and also inform partners of relevant peer support groups. Studies of the effects of implementation of supportive measures should be carried out.

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Appendix 1

Information about the study and informed consent form for participants in Study I

Sørlandet sykehus HF

Forespørsel til annen forelder/foresatt om deltakelse i forskningsprosjektet:

Barn av pasienter med alvorlig sykdom eller rusmiddelmisbruk

Bakgrunn og hensikt

Formål med forskningsprosjektet er å finne ut hvor mange barn (0-18 år) som er pårørende til foreldre med alvorlig somatisk sykdom, psykisk sykdom eller rusmiddelavhengighet, og kartlegge deres behov for informasjon og oppfølging i forbindelse med sykdommen. Videre ønsker vi å få informasjon fra journalene om sykehuset følger lovpålagte rutiner for å vurdere behov hos barn som er pårørende og bidrar til nødvendig hjelp og støtte til familiene.

Hva innebærer studien?

Studien innebærer en undersøkelse av dine og barnas opplevelse knyttet til sykdommen, behovet for helse- og omsorgstjenester, og i hvilken grad dere kjenner dere ivaretatt av helsepersonell. For å vurdere sykehusets rutiner for den lovpålagte kartlegging av barn som pårørende vil prosjektpersonale se om dette har blitt registrert i forelderens journal og gi et spørreskjema til behandler ved sykehuset.

Dersom du sier ja til å delta i undersøkelsen, vil prosjektmedarbeideren ta kontakt for å avtale utfylling av spørreskjema via internett eller eventuelt papirskjema. Dersom barnet som er med i undersøkelsen er under 8 år, vil foreldrene bli bedt om å svare på vegne av barnet. Spørreskjemaet gjelder opplevelser knyttet til sykdommen og behov for informasjon og oppfølging. Vi ønsker å ha mulighet til å kontakte deg igjen etter ett år for å spørre om du vil være med på en samtale om hvordan det har gått videre og om hvordan helsetjenestene har fulgt opp deg og familien. Vi ber også om å få innhente opplysninger om barnet fra lærer i skole eller barnehage.

Mulige fordeler og ulemper

Dersom du velger å delta i studien, vil du bidra til at helseforetakene får mer kunnskap om hvordan de kan ivareta foreldre og barns lovfestede rettigheter på en bedre måte. Intervjuene vil også kunne bidra til mer kunnskap og større åpenhet om sykdom i din familie. Noen kan oppleve at det er krevende å snakke om vanskelige tema, men vi vet fra tidligere forskning at både foreldre og barn likevel synes at det er positivt å bli spurt om sine erfaringer.

Hva skjer med informasjonen om deg?

Forskningsgruppen som behandler informasjon fra deg og din familie er autoriserte personell med taushetsplikt. Data blir oppbevart i henhold til krav fra myndighetene. Papirskjema blir nedlåst i stålskuffer, og elektronisk data blir lagret på en sikker datamaskin på sykehuset. Bare forskergruppen vil ha adgang til opplysningene. Offentliggjøring av resultatene vil bli gjort på gruppenivå og det vil ikke være mulig å identifisere deg i resultatene når disse publiseres.

Frivillig deltakelse
Deltakelse i undersøkelsen er frivillig for deg, barnet ditt og den andre forelder. Du/dere kan når som helst trekke dere fra undersøkelsen uten å oppgi en begrunnelse. Dette vil ikke få konsekvenser for din videre behandling på sykehuset.

Personvern

De opplysningene som registreres om deg og din familie, er slike opplysninger som vanligvis innhentes for å undersøke situasjonen til barn som er pårørende og deres familie. Prosjektet anbefalt av Personvernombudet ved sykehuset/helseforetaket og godkjent av Regional komité for medisinsk og helsefaglig forskningsetikk (sør-øst).

Rett til innsyn og sletting av opplysninger om deg og sletting av prøver

Opplysninger som registreres om deg vil være informasjon du selv gir. Du/dere har rett til innsyn i og få korrigert eventuelle feil i opplysningene vi har registrert. Dersom du/dere trekker deg fra prosjektet kan du/dere kreve å få slettet innsamlede opplysninger til forskningsformål med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Samarbeid og økonomi

Forskningsprosjektet er et samarbeid mellom fem sykehus/helseforetak i Norge (Akershus universitetssykehus HF som er forskningsansvarlig for prosjektet, Nordlandssykehuset HF, Vestre Viken HF, Sørlandet sykehus HF, Helse Stavanger HF/Rogaland A-senter), Regionsenter for barn- og ungdoms psykisk helse- RBUP Øst og Sør og BarnsBeste - nasjonalt kompetansenettverk for barn som pårørende. Hovedfinansieringen for prosjektet er fra Norges forskningsråd.

Informasjon om utfallet av studien

Alle deltakere som ber om det vil få tilbakemelding om resultater av forskningsprosjektet. Resultatene vil være på gruppenivå.

Dersom du/dere har spørsmål til studien eller ønsker å trekke dere, kan du/dere ta kontakt med lokal koordinator: *Bente Hjemdahl, tlf 4889 0662*

Samtykkeerklæring er på side 3

Samtykke fra annen forelder/foresatt om å delta i forskningsprosjektet

For prosjektmedarbeider:

Informasjon om forskningsprosjektet er blitt gitt av:

____ Dato:________________

(Navn på prosjektmedarbeider)

For annen forelder/foresatt:

Jeg har fått tilfredsstillende informasjon om forskningsprosjektet og samtykker til å delta i undersøkelsen. Informasjon kan brukes slik som det er beskrevet ovenfor.

_____________________________________	_____________________________________
Sted og dato	Underskrift annen forelder/foresatt
	_____________________________________
	Navn med store bokstaver

Jeg gir samtykke til at barnets lærer/ansatt i skole/barnehage også blir bedt om å gi informasjon om barnet. Ja ( ) Nei ( )

_____________________________________	_____________________________________
Sted og dato	Underskrift annen forelder/foresatt

Kopi: Pasient/foresatte og forskningsmappe

Appendix 2

Approval No. 2012/1176A Regional Committee for Medical Research Ethics (Study I)

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK sør-øst	Jørgen Hardang	22845516	08.11.2012	2012/1176/REK sør-øst A
			Deres dato:	**Deres referanse:**
			19.10.2012	

Vår referanse må oppgis ved alle henvendelser

Torleif Ruud

Akershus universitetssykehus
Avdeling forskning og utvikling, Divisjon psykisk helsevern

2012/1176 Barn av pasienter med alvorlig sykdom eller rusmiddelmisbruk

Prosjektleder: Torleif Ruud

Forskningsansvarlig**:** Akershus universitetssykehus

Søknaden ble behandlet i møtet 16.08.2012. Komiteen gjorde et utsettende vedtak. Søker har i tilbakemelding mottatt 8.11.2012 svart på komiteens merknader. Søknaden ble behandlet på nytt i møtet 18.11.2012.

Til spørsmål 1 og 2 om formålet med undersøkelsen:
Som svar på det første spørsmålet redegjør søker utførlig om formålet med prosjektet. Målet er å bidra til ny kunnskap om forekomsten av barn som pårørende og hva som kjennetegner barna og foreldrene og deres livssituasjon og i hvilken grad barna blir oppdaget og fulgt opp av helsepersonell. I dette ligger også spørsmålet om helsetilstand og livssituasjon hos barna og foreldrene. Det presiseres at spørreskjemaene som benyttes ikke kan gi informasjon om diagnoser. ”Men vi får data om utbredelse og alvorlighetsgrad av helseproblemer og noe om hvilke konsekvenser dette synes å ha for barna.” ”En del av barna vil ha helseproblemer og ha behov for behandling, og det er viktig å få kunnskap om omfanget av dette.” ”Vår undersøkelse kombinerer derfor kartlegging av barn og unges psykiske helse med kartlegging av deres livssituasjon og opplevelse av den, samt foreldrenes opplevelse av sin situasjon, barnas situasjon og den hjelp de får.”

Det antas at undersøkelsen også skal kunne gi helsetjenester, brukerorganisasjoner og helsemyndigheter kunnskap om hva som trenger å forbedres.

I en videre sammenheng tenker en at resultatene av denne studien skal kunne gi grunnlag for videre forskning blant annet med utforming av en intervensjonsstudie.

Til spørsmål 2 om gjennomførbarhet:
I tilbakemeldingen redegjøres det grundig for planleggingen av prosjektet, for de ressurser som avsettes i form av kvalifisert personell, finansiering og tidsbruk i forbindelse med innsamling og analyse av data og publisering av resultater

Ulike sider ved utvelgelse og rekruttering av pasienter og barn blir gjennomgått. Målet er å få et mest mulig representativt utvalg av barn av pasienter som er i kontakt med spesialhelsetjenesten innenfor de tre gruppene somatikk, psykiatri og rus. Det samme gjelder utvalget av poliklinikker og døgnposter med tanke på rekruttering fra områder med ulik befolkningstetthet.

Spørsmålet om lærerne som informanter vil komme inn etter at foreldrene har blitt kjent med prosjektet og samtykker til at læreren også bidrar med å svare på et spørreskjema.

Til spørsmål 3:
Data skal i hovedsak innhentes ved hjelp av et omfattende apparat av spørreskjemaer. Informantene befinner seg på ulike utviklingstrinn og i forskjellige situasjoner. Derfor er det gjort et omfattende arbeid for å sette sammen, å utforme og å tilpasse spørreskjemaene. Det er gjennomført testing av spørreskjemaer på 7 barn og 8 foreldre. Det er vedlagt spørreskjemaer for følgende grupper:

Spørreskjema barn 8-13 år.
Spørreskjema ungdom 14–18 år.
Spørreskjema pasient med barn 15–20 mnd.
Spørreskjema pasient med barn 8-13 år.
Spørreskjema pasient med ungdom 14–18 år.
Spørreskjema annen voksen med barn 8-13 år.
Spørreskjema annen voksen med ungdom 14–18 år.
Spørreskjema barnehageansatt.
Spørreskjema lærer for barn 8-13 år.
Spørreskjema lærer for ungdom 14–18 år.
Spørreskjema behandler/helsepersonell.

Barn på 6 og 7 år skal intervjues. For barn fra 0 til 5 skal det innhentes opplysninger fra foreldrene. Etter innsamling vil data bli avidentifisert og lagret som krypterte filer på forskningsserver på Akershus universitetssykehus.

Til spørsmål 4:
Undersøkelsen gjelder barn fra 0 til 18 år. Det antas at det kan komme til å bli inkludert 400 barn mellom 0 og 7 år og 500 barn i alderen 8-18 år. Barna informeres via foreldrene. Det er laget en tilpasset informasjonsbrosjyre.

Under utformingen av spørreskjemaene er det lagt vekt på å bruke formuleringer som ikke er for provoserende, ”men som samtidig gir åpning for at barn og unge kan formidle sine opplevelser og erfaringer”. Også ved utfylling av spørreskjema vil en intervjuer være til stede for å svare på spørsmål, observere og følge opp ved behov i etterkant.

Til spørsmål 5:
Om bruk av lærer som informanter heter det: ” Lærere er viktige personer i barns liv. De ser barna hver dag gjennom år og observerer barnets kontakt og samvær med andre barn. Forskning på barn og unge viser at lærere er viktige informanter om barns psykiske helse, trivsel og fungering. Lærere er derfor mye brukt som informanter både i klinisk arbeid og i forskning på barn, og flere av de mest brukte spørreskjema er utviklet med en egen versjon for utfylling av lærere.”

Til spørsmål 5:
Forskningsansvarlig for forskningsprosjektet er Akershus universitetssykehus.

Komiteens vurdering

Komiteen hadde omfattende spørsmål og innvendinger, spesielt med hensyn formål, til til antall forskningsspørsmål og gjennomførbarhet av et så stort prosjekt. I tilbakemeldingen er det grundig redegjort for alle disse forhold. Det er også avklart at selv om prosjektet dels retter seg mot hvordan helsetjeneste fungerer overfor barn som pårørende, så er formålet også å kartlegge helsetilstand og eventuelle behov for behandling.

På denne bakgrunn vurderer komiteen prosjektet for tilfredsstillende opplyst i forhold til formål og design og anser at det er grunnlag for å anta at det vil kunne gi svar på de forskningsspørsmål som er formulert.

Vedtak
Komiteen godkjenner at prosjektet gjennomføres i samsvar med det som framgår av søknaden og av tilbakemelding på komiteens spørsmål.

Godkjenningen gjelder til 31.12.2016.

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

Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veileder for «Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse- og omsorgssektoren». Opplysningene skal ikke oppbevares lenger enn det som er nødvendig for å gjennomføre prosjektet, deretter skal opplysningene anonymiseres eller slettes.

Prosjektet skal sende sluttmelding på eget skjema, se helseforskningsloven § 12, senest et halvt år etter prosjektslutt.

Med vennlig hilsen

Gunnar Nicolaysen
Professor
Leder

Jørgen Hardang
Komitésekretær

Kopi til: postmottak@ahus.no**;** *kso@nlsh.no; oskjelda@vestreviken.no; inger.kari.nerheim@sus.no; kjersti.egenberg@ras.rl.no; kah@r-bup.no; siri.gjesdahl@sshf.no; anne.wenche.emblem@sshf.no*

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*

Appendix 3

Approval information on the five hospitals participating in the larger study (Study I)

Oversikt over godkjenninger fra de fem helseforetakene som deltar i multisenterstudien Barn av pasienter med alvorlig sykdom eller rusmiddelmisbruk

Henvendelsene til helseforetakene om godkjenning ved helseforetakene og deres personvernombud ble sendt til helseforetakene i desember 2012. Helseforetakene hadde den gang ulike ordninger når det gjaldt hvem som skulle godkjenne deltagelse i slike samarbeidsprosjekter. Noen hadde eget personvernombud, mens det andre steder var en forskningsleder som skulle godkjenne. Vestre Viken brukte personvernombudet ved Oslo universitetssykehus, slik at godkjenningen deres kom derfra.

Godkjenningene hadde også ulike utforminger (slik sidene nedenfor viser), men godkjenning i form av brev eller påtegnede meldeskjema, eller en kort setning i en epost. Det tok fra tre uker til ni måneder å få godkjenninger fra helseforetakene, så datainnsamlingen kom i gang på ulike tidspunkt.

Godkjenningene på sidene nedenfor er fra de fem helseforetakene i denne rekkefølgen:

1. Akershus universitetssykehus HF

2. Vestre Viken HF (fra personvernombudet ved Oslo universitetssykehus)

3. Sørlandet sykehus HF

4. Helse Stavanger HF

5. Nordlandssykehuset HF

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	☐ Elever/studenter/barnehagebarn	☒ Pasienter	☐ Tilfeldig utvalgte
☐ Adgangskontrollerte	☐ Medlemmer	☒ Kunder/klienter/brukere	☐ 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

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[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

Personvernombudet for forskning og kvalitetssikring
Kompetansesenter for personvern og informasjonssikkerhet
Oslo universitetssykehus HF

PERSONVERNOMBUDETS UTTALELSE

Til:	Torleif Ruud
Kopi:	
Fra:	Personvernombudet for forskning og kvalitetssikring
Saksbehandler:	Stein Vetland
Dato:	6. september 2013
Offentlighet:	Ikke unntatt offentlighet
Sak:	Personvernombudets uttalelse om innsamling og behandling av personopplysninger
Saksnummer/ Personvernnummer:	2013/12722

Personvernombudets uttalelse om innsamling og behandling av personopplysninger i prosjektet ”Barn som pårørende”

Viser til innsendt melding om behandling av personopplysninger / helseopplysninger. Det følgende er et formelt svar på meldingen. Forutsetningene nedenfor må være oppfylt før rekruttering av pasienter til studien kan starte.

Personvernombudet har vurdert den planlagte databehandlingen av personopplysninger / helseopplysninger til å tilfredsstille de krav som stilles i helse- og personvernlovgivningen.

Personvernombudet har ingen innvendinger til at den planlagte databehandlingen av personopplysninger / helseopplysninger kan igangsettes under forutsetning av følgende:

1. Forskningsansvarlig / databehandlingsansvarlig er Akershus universitetssykehus ved adm. dir.
2. Behandling av personopplysningene / helseopplysninger i studien skjer i samsvar med og innenfor det formål som er oppgitt i meldingen.
3. Studien må vurderes og godkjennes av Regional komité for medisinsk og helsefaglig forskningsetikk (REK), og eventuelle merknader må følges..
4. Samtykke benyttes, inklusive eventuelle markerte tillegg og endringer foretatt av personvernombudet. Eventuelle fremtidige endringer som berører formålet, utvalget inkluderte eller databehandlingen må forevises personvernombudet før de tas i bruk.

5. Data lagres som oppgitt i meldingen. Kryssliste som kobler avidentifiserte data med personopplysninger lagres som angitt i meldingen og oppbevares separat på prosjektleders avlåste kontor på sykehuset.
6. Data slettes eller anonymiseres senest 31.desember 2016 ved at krysslisten slettes og eventuelle andre identifikasjonsmuligheter i databasen fjernes.
7. Det må etableres en databehandleravtale med RBUP og underleverandører. Før databehandleravtale kan inngås, må det foreligge en risikovurdering som er godkjent av Personvernombudet.
8. Dersom formålet, utvalget av inkluderte eller databehandlingen endres må personvernombudet gis forhåndsinformasjon om dette.

Prosjektet er registrert i oversikten over tilrådinger og uttalelser til forskning som Personvernombudet fører for sykehuset. Oversikten er offentlig tilgjengelig.

Med vennlig hilsen
for Personvernombudet for forskning og kvalitetssikring

Stein Vetland, personvernrådgiver
Kompetansesenter for personvern og informasjonssikkerhet
Stab pasientsikkerhet og kvalitet
Oslo universitetssykehus HF

Epost: personvern@oslo-universitetssykehus.no
Web: www.oslo-universitetssykehus.no/personvern

SØRLANDET SYKEHUS

Fagavdelingen
Forskningsenheten

Vår dato
04.02.2013
Deres dato
12.12.2012

Vår referanse
13/00372-2 - 306
Deres referanse

Torleif Ruud
Akershus universitetssykehus HF

1478 LØRENSKOG

Samarbeidsprosjekt mellom SSHF og Akershus universitetssykehus Hf (Ahus) - Barn som pårørende - Children of pasients with severe illness or substance abuse (FoU-prosjekt)

Viser til søknad om datainnsamling: ”Barn som pårørende – Children of patients with severe illness or substance abuse: Prevalence, identification, perceived needs, services received and outcome.”

Søknaden er forskningsfaglig godkjent 07.01.2013.

Med vennlig hilsen
Sørlandet sykehus HF

Kirsten Andersen

Kirsten Andersen
Konsulent

Postadresse
Sørlandet sykehus HF
Forskningsenheten
Postboks 416
4604 Kristiansand

Besøksadresse
Eg
4615 Kristiansand

Telefon
+47 38 07 33 69
Telefaks
+47 38 07 41 73
Bankkonto
1503.27.07405

Administrasjonsadresse
Sørlandet sykehus HF
Postboks 416
4604 Kristiansand
Telefon
03738

Foretaksregisteret
NO 983 975 240 MVA
Hjemmeside
www.sshf.no
e-post
postmottak@sshf.no

Stavanger Universitetssjukehus
Helse Stavanger HF
Forskningsavdelingen

Notat

Til:
Åshild Skogerbø

Kopi til:
fagsjef Sølve Braut
divisjonsdirektør Psykiatrisk divisjon

Dato: 28.01.2013
Fra: forskningssjef Inger Økland
Arkivref: 2013/434 - 4008/2013

Godkjennelse av forskningsprosjekt - ID295

Forskningsprosjektet: «Barn som pårørende».

Det vises til søknad vedrørende oppstart av ovennevnte forskningsprosjekt. Prosjektet har vært vurdert av forskningsansvarlig og prosjektet er registrert i vår database med intern id: ID295

Nødvendige tillatelser foreligger. Basert på disse og forskningsprotokoll godkjennes oppstart av prosjektet.

Forskningsavdelingen ønsker å minne om at:

- prosjektet må gjennomføres i henhold til protokollen og ved endringer må endringsmelding sendes
- dersom prosjektet er godkjent av REK, må søknad og godkjennelse av REK følges
- foreligger det godkjennelse fra Personvernombud må likeledes denne følges
- behandling av helse- og personopplysninger skjer i samråd med og innenfor det formål som er beskrevet
- ved tilgang til registre, skjer dette i overensstemmelse med taushetspliktbestemmelsene
- data lagres avidentifisert på helseforetakets forsknings/kvalitetsserver etter de regler som gjelder for bruk av denne
- dersom innhenting av pasientopplysninger baserer seg på samtykke, må samtykkeskjemaet oppbevares
- data skal slettes eller anonymiseres ved prosjektslutt

Dersom prosjektet ikke starter og/eller blir avbrutt må melding sendes til Forskningsavdelingen. Likeledes sendes en kort sluttrapport.

Forskningsavdelingen ønsker lykke til med gjennomføring av prosjektet.

Torleif Ruud

Fra:	Sørgaard Knut <Knut.Sorgaard@nordlandssykehuset.no>
Sendt:	14. januar 2013 11:11
Til:	Torleif Ruud
Kopi:	Leinan Alf
Emne:	SV: Meldeskjema om prosjekt Barn som pårørende

Ja – alt ok. Har oversett noe epost.
Mvh K

Fra: Torleif Ruud [mailto:torleif.ruud@ahus.no]
Sendt: 11. januar 2013 08:46
Til: Leinan Alf; Sørgaard Knut
Emne: SV: Meldeskjema om prosjekt Barn som pårørende

Hei Knut

Har du fått sett på dette?
Det haster for oss å få personvernombudets godkjenning på plass for å kunne starte datainnsamlingen i løpet av januar.

Hilsen Torleif

Torleif Ruud
avdelingssjef, professor

Akershus universitetssykehus HF
FOU-avdeling psykisk helsevern
1478 LØRENSKOG
Tlf: +47 02900 (sentralbord)
Tlf: +47 6796 8773 (direkte)
Mobil: +47 97546760
E-Post: torleif.ruud@ahus.no
Web: www.ahus.no
Tenk miljø – ikke skriv ut denne om det ikke er absolutt nødvendig!

Fra: Leinan Alf [mailto:Alf.Leinan@nordlandssykehuset.no]
Sendt: 19. desember 2012 14:08
Til: Sørgaard Knut
Kopi: Torleif Ruud
Emne: VS: Meldeskjema om prosjekt Barn som pårørende

Hallo Knut

Dette prosjektet faller nok utenfor mitt mandat,
kan du se næmere på dette?

mvh
Personvernombud
Alf Leinan

Fra: Torleif Ruud [torleif.ruud@ahus.no]
Sendt: 12. desember 2012 15:39
Til: Leinan Alf
Kopi: Skogøy Bjørg Eva; Sørgaard Knut; Solveig Lundsvoll
Emne: Meldeskjema om prosjekt Barn som pårørende

Til personvernombudet
Nordlandssykehuset HF

Oversender herved meldeskjema med diverse vedlegg for stort prosjekt som er under forberedelse, og der datainnsamling skal starte primo januar 2013.
Ta kontakt om noe er uklart.

Hilsen Torleif

Torleif Ruud
avdelingssjef, professor

Akershus universitetssykehus HF
FOU-avdeling psykisk helsevern
1478 LØRENSKOG
Tlf: +47 02900 (sentralbord)
Tlf: +47 6796 8773 (direkte)
Mobil: +47 97546760
E-Post: torleif.ruud@ahus.no
Web: www.ahus.no

Appendix 4

Additional project description to Regional Committee for Medical Research Ethics, including interview guide and information about the study and informed consent form for participants in Study III

Prosjektbeskrivelse levekårsundersøkelser for voksne pårørende ved rusproblemer, Sørlandet Sykehus HF.

Undersøkelsen som endringsmeldingen gjelder, gjøres på oppdrag fra Helsedirektoratet. Studien inngår som en delstudie i prosjektet *Barn av pasienter med alvorlig sykdom eller rusmiddelmisbruk* (2012/1176/REK sør-øst A) og med samme avslutningsdato.

Prosjektleder for hovedprosjektet og delstudien det her søkes om, er professor Torleif Ruud, avdelingssjef, FOU-avdeling psykisk helsevern, Akershus universitetssykehus (Ahus). Divisjonsdirektør Trond Rangnes ved Divisjon psykisk helsevern, Ahus, er forskningsansvarlig.

Formålet med delstudien som beskrives her, er å få frem hvilke erfaringer og egenopplevelser voksne pårørende har som følge av å leve sammen med eller tett innpå en nærstående med rusproblemer. I tillegg er formålet å belyse hvordan de pårørende mestrer hverdagen, og hvilke tiltak de pårørende har behov for.

Oppdraget fra Helsedirektoratet innebærer å beskrive levekårene til voksne pårørende til personer med rusproblemer. Beskrivelsen skal inneholde en oppsummering av levekårene til de voksne, og vil supplere kvantitative data fra ut fra prosjektet *Barn av pasienter med alvorlig sykdom eller rusmiddelmisbruk*. For delstudien det her søkes om, innebærer oppdraget å gjennomføre kvalitative intervju med ca 30 voksne pårørende, ved hjelp av semi-strukturerte intervju. Hvordan intervjuene skal gjennomføres, hvem som skal rekrutteres, samt intervjuguiden, er utarbeidet i samarbeid med brukerorganisasjonene A-larm og Landsforeningen mot stoff (LMS). Det vil bli rekruttert pårørende fra deltakere i hvoedstudien og/eller fra medlemslistene til de ulike brukerorganisasjonene.

ORGANISERING

Prosjektansvarlig for både hovedstudien *"Children of patients with severe illness or substance abuse: Prevalence, identification, perceived needs, services and outcome"* og her beskrevne levekårsundersøkelse er divisjonsdirektør Trond Rangnes, Divisjon psykisk helsevern, Akershus universitetssykehus (AHus). Prosjektleder for begge (hovedstudien og delstudien) er Torleif Ruud, avd.sjef ved fou-avdelingen, psykisk helsevern ved Ahus, samt professor ved Klinikk for helsetjeneste og psykiatri, Institutt for klinisk medisin, Universitetet i Oslo.

Sørlandet sykehus HF har fått ansvar for gjennomføringen av oppdraget med delstudien, hvor lokal koordinator for både multisenterstudien og delstudien det søkes om, er stipendiat Bente Hjemdahl. Hun har mastergrad i psykososialt arbeid fra Universitetet i Oslo (institutt for psykiatri), og er knyttet til et veletablert forskningsmiljø ved Avdeling for rus- og avhengighetsbehandling, Sørlandet sykehus HF. Forsker phd Bente Weimand (lokal koordinator ved Ahus, førsteamanuensis ved Høgskolen i Oslo og Akershus) er veileder for den kvalitative studien.

Bente Hjemdahl er knyttet til forskergruppe/prosjektgruppe det kvantitative prosjektet, som ledes av prosjektleder Torleif Ruud, og hvor lokale koordinatorer og stipendiater/forskere fra de ulike tilknyttede helseforetak også er tilknyttet. Prosjektgruppe for den kvalitative undersøkelsen består av representanter for de ulike brukerorganisasjonene A-Larm og LMS, samt Bente Hjemdahl og Bente Weimand.

METODE

Datainnsamling til kvalitativ undersøkelse gjøres ved hjelp av semistrukturerte intervju blant 30 voksne nære pårørende til rusmisbrukere. Disse rekrutteres i samarbeid med brukerorganisasjonene A-Larm eller LMS, samt fra den kvantitative undersøkelsen og/eller andre brukerfora dersom utvalget fra de nevnte brukerorganisasjonene blir for lite eller for smalt.

Det er utarbeidet intervjuguide i samarbeid med brukerorganisasjonene, basert på ønskede tema som disse ønsker belyst. De semi-strukturerte dybdeintervjuene vil gjøres med lydopptak, transkribering og omfattende kvalitative analyser, og brukerorganisasjonene er tett involvert i både planlegging, analysearbeid og tolkning av resultatene.

- Lokal prosjektansvarlig (hovedansvarlig for rekruttering og gjennomføring av intervjuer):
  Sosionom med videreutdannelse i addiktologi (rusterapeut), og med mastergrad i psykososialt arbeid (selvmord, rus, vold og traumer) fra Universitetet i Oslo.

  15 års erfaring som individual- og gruppeterapeut i familiebasert behandling i spesialisthelsetjenesten (rusinstitusjon og poliklinikk); pasient- og pårørendesamtaler.

  5 års erfaring som undervisningsleder i tverrfaglig spesialisert behandling (FoU-enhet) med veiledning av sosionomstudenter på ulike prosjektarbeid i avdelingen.

  Erfaring med intervju fra eget bachelorprosjekt sosionom, samt som prosjektmedarbeider i annet PhD- prosjekt, med rekruttering og individualsamtaler med informanter innlagt i institusjon, samt 6 måneder etter utskrivelse.

- Lokal prosjektmedarbeider:
  Erfaring med kvalitative intervjuer fra eget mastergradsprosjekt, samt årelang erfaring med samtaler med rusmisbrukende mødre og deres familier.

- Veileder, sentral forankring:
  Forsker, psykiatrisk sykepleier (PhD), med erfaring fra både individuelle og fokusgruppeintervju, fra doktorgradsstudier og pågående prosjekt. Erfaring i opplæring av intervjuere i forskningsprosjekt. Tidligere mangeårig erfaring som høgskolelektor med studentveiledninger og opplæring av studenter som skulle gjennomføre prosjekt og klientsamtaler. Mange års erfaring i undervisning og veiledning i vitenskapelig metode.

Håndtering av opptak:

Lydopptak av intervjuene oppbevares på kryptert minnepinne hvor kun lokal prosjektansvarlig har tilgang til passord. Denne oppbevares i låst brannsikkert skap ved FoU-enhet ved Avdeling for rus- og avhengighetsbehandling, Sørlandet sykehus. Kodenøkkel som kobler informanter og innsamlete data oppbevares nedlåst og atskilt fra andre opplysninger i eget låsbart og brannsikkert skap, som kun prosjektleder har tilgang til.

Ved avslutning av prosjektet vil alle innsamlede data anonymiseres, og lydopptakene vil bli destruert. Anonymisering av data fordrer at opplysninger om navn og bakgrunnsopplysninger som bosted, alder og kjønn) holdes atskilt fra lydopptakene, slik at ingen enkeltpersoner kan gjenkjennes i datamaterialet. Det er kun lokal prosjektleder som har tilgang til de data som kan identifisere enkeltpersonene.

Transkribering av intervjuene vil bli gjort ved Akershus Universitetssykehus, eller av lokal prosjektansvarlig**.** Intervjuene transkriberes i anonymisert form. Det er kun anonymiserte intervjutranskript som formidles til veileder. Dette gjøres enten ved å sende papirformat i ordinær post til veileders arbeidssted eller ved å levere personlig.

RESULTATER

Hovedrapport om levekårsundersøkelsen for voksne pårørende til rusmisbrukere skal leveres Helsedirektoratet innen utgangen av 2014. Den skal belyse i hvor stor grad de pårørende er identifisert og hvor stor andel av disse som opplever problemer, hvordan de opplever hjelp og oppfølging, og utfall for dem og familiene. I tillegg skal rapporten gi svar på hvilke behov det er for forbedring og identifikasjon av pårørende til rusmisbrukere, og hvilken hjelp de i sin helhet beskriver at de har behov for.

Hovedrapporten vil beskrive levekår for voksne pårørende, og hvordan situasjonen som pårørende virker inn på deres livssituasjon og livskvalitet. Resultatene fra den kvalitative studien vil bli beskrevet og vil supplere og utdype resultatene fra den kvantitative studien i hovedrapporten om levekårsundersøkelsen. Denne delen vil også inneholde oppsummering av hvordan dette er sammenlignet med situasjonen for pårørende til psykisk syke eller til pasienter med alvorlig somatisk sykdom (kreft/nevrologi). Litteraturgjennomgangen leveres i en egen rapport og inkluderes ikke i hovedrapporten.

Helsedirektoratet har også gitt tilsagn til at data fra delstudien som her beskrives, vil være tilgjengelig for bruk i fremtidig doktorgradsstudier for Bente Hjemdahl.

Intervjuguide til bruk i kvalitativ levekårsundersøkelse blant voksne pårørende til rusmisbrukere.

1. **Kan du si noe om hvordan du opplever/har opplevd å være pårørende til en rusmisbruker?**
2. **Hvordan har du opplevd din *rolle* som pårørende?**
3. **Hvordan har du opplevd å få / ikke få hjelp som pårørende til en rusmisbruker?**
4. **Er det du som pårørende har erfart som positivt, som du kan gjøre nytte av?**

Disse 4 overordnete spørsmålene vil følges opp av utdypende spørsmål, for å få fram eksempler, ytterligere refleksjoner og variasjoner i informantenes opplevelser.

De utdypende spørsmålene tas i bruk ettersom det passer informantens fortelling. Nedenfor er listet opp eksempler på noen slike oppfølgingsspørsmål, andre kan komme til under intervjuet:

- **Hvor lenge har det vært slik?,**
- **Har du noe eksempel på det?,**
- **Hvordan kunne dette eventuelt ha vært håndtert annerledes (av hvem?), , og hva skulle i så fall til?,**
- **Hva tenker du om dette i ettertid?**
- **Hvordan kunne du ønske at det skulle ha vært?**
- **Har denne erfaringen hatt innvirkning på deg, og i så fall hvordan?**
- **Hvordan kan eventuelt andre i liknende situasjon som deg dra nytte av din erfaring?**

Sørlandet sykehus HF

Forespørsel til pårørende om deltakelse i levekårsundersøkelse blant nære pårørende til rusmisbrukere.

Bakgrunn og hensikt

I forbindelse med en pågående en nasjonal undersøkelse om barn som pårørende (*”Barn av foreldre med alvorlig sykdom”)*, skal det undersøkes hvordan det er å være voksen pårørende til mennesker som er rusmisbrukere. Formål med denne levekårsundersøkelsen, er å få frem hvilke erfaringer og opplevelser disse pårørende har som følge av å leve sammen med eller tett innpå en nærstående med rusproblemer. I tillegg er formålet å belyse hvordan pårørende mestrer hverdagen, og hvordan situasjonen som pårørende virker inn på områder som livssituasjon og livskvalitet. Videre er formålet å finne ut hvilke tiltak pårørende har behov for, og hvilke erfaringer pårørende har som kan være til nytte for andre. Resultatene av undersøkelsen vil bli brukt både i vitenskapelige publikasjoner, og i en rapport til Helsedirektoratet.

Hva innebærer studien?

Undersøkelsen innebærer å forstå mer om hvordan det er å være nær pårørende til en rusmisbruker, deres behov for helse- og omsorgstjenester, og i hvilken grad pårørende kjenner seg ivaretatt av helse- og omsorgstjenestene. For å undersøke dette, vil det gjennomføres intervju med pårørende om temaene nevnt over. Intervjuet vil ta cirka en time.

Dersom du sier ja til å delta i undersøkelsen, vil vi ta kontakt for å gjøre avtale om tid og sted for et intervju. Selv om det benyttes lydopptaker for å best mulig la deg fortelle dine opplevelser, har prosjektmedarbeideren taushetsplikt og ansvar for å ivareta din anonymitet.

Mulige fordeler og ulemper

Dersom du velger å delta i studien, vil du bidra til at helsetjenestene får mer kunnskap om hvordan de kan ivareta pårørendes lovfestede rettigheter på en bedre måte. Du vil også bidra til økt kunnskap om pårørende til rusmisbrukeres levekår. Du vil også kunne bidra til mer kunnskap og større åpenhet om hvordan det er å leve tett på en rusmisbruker. Noen kan oppleve at det er krevende å snakke om slike tema, men vi vet fra tidligere forskning at pårørende likevel synes at det er positivt å bli spurt om sine erfaringer. Du bestemmer selv hvor mye du vil fortelle.

Hva skjer med informasjonen om deg?

Forskningsgruppen som behandler informasjon fra deg er autoriserte personell med taushetsplikt. Bare forskergruppen vil ha adgang til opplysningene. Offentliggjøring av resultatene vil bli gjort anonymisert og på gruppenivå, og det vil ikke være mulig å identifisere deg i resultatene når disse publiseres.

Frivillig deltakelse

Deltakelse i undersøkelsen er frivillig. Du kan når som helst trekke deg fra undersøkelsen uten å oppgi en begrunnelse. Dette vil ikke få konsekvenser for din eventuelle videre kontakt med spesialisthelsetjenesten.

Personvern

De opplysningene som registreres om deg, er slike opplysninger som vanligvis innhentes for å undersøke situasjonen til pårørende. Prosjektet er anbefalt av Personvernombudet ved sykehuset/helseforetaket og godkjent av Regional komité for medisinsk og helsefaglig forskningsetikk (sør-øst).

Rett til innsyn og sletting av opplysninger om deg og sletting av prøver

Opplysninger som registreres om deg vil være informasjon du selv gir. Du har rett til innsyn i, og få korrigert eventuelle feil i opplysningene vi har registrert. Dersom du trekker deg fra prosjektet kan du kreve å få slettet innsamlede opplysninger til forskningsformål med mindre opplysningene allerede er inngått i rapporter eller brukt i vitenskapelige publikasjoner.

Samarbeid og økonomi

Levekårsundersøkelsen er et samarbeid mellom Sørlandet sykehus HF, Akershus Universitetssykehus (som har prosjektledelsen), Helsedirektoratet og brukerorganisasjonene A-Larm og LMS (Landsforeningen mot stoffmisbruk). Hovedfinansieringen for prosjektet er fra Helsedirektoratet. Prosjektleder er professor Torleif Ruud, avdelingssjef ved fou-avdelingen, psykisk helsevern ved Ahus.

Informasjon om utfallet av studien

Alle deltakere som ber om det vil få tilbakemelding om resultater av forskningsprosjektet. Resultatene vil være på gruppenivå, og Helsedirektoratets sluttrapport vil være tilgjengelig når den er ferdig.

Dersom du har spørsmål til studien eller ønsker å trekke deg, kan du ta kontakt med lokal koordinator:
Bente Hjemdahl, tlf 4889 0662

Samtykkeerklæring er på side 3

Samtykke fra pårørende om å delta i forskningsprosjektet/levekårsundersøkelsen:

For prosjektmedarbeider:

Informasjon om forskningsprosjektet er blitt gitt av:

_______________________________________ Dato:______________

(Navn på prosjektmedarbeider)

For den pårørende:

Jeg har fått tilfredsstillende informasjon om levekårsundersøkelsen blant voksne pårørende til mennesker med rusmisbruk, og samtykker til å delta i undersøkelsen. Informasjon kan brukes slik som det er beskrevet ovenfor.

______________________________	______________________________
Sted og dato	Underskrift informant (pårørende)
	______________________________
	Navn med store bokstaver

____

Kontaktopplysninger (tlf/ epost)

____

Kopi: Informant og forskningsmappe

Appendix 5

Approval No. 2012/1176A Regional Committee for Medical Research Ethics, additional approvals (Study III)

Fra: post@helseforskning.etikkom.no [mailto:post@helseforskning.etikkom.no]
Sendt: 31. januar 2014 14:44
Til: Torleif Ruud
Kopi: 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 Olav Rangnes
Emne: Sv: REK sør-øst 2012/1176 Barn av pasienter med alvorlig sykdom eller rusmiddelmisbruk

Vår ref. nr.: 2012/1176 A

Kjære Torleif Ruud,

Vi viser til mottatt endringsmelding datert 21.01.2014.

I prosjektendringen søkes det om godkjennelse for to delstudier som skal inngå i hovedprosjekt. Disse delstudiene omfatter levekår for barn av personer med rusproblemer og levekår for voksne pårørende til personer med rusproblemer. Det skal i delprosjektene innsamles opplysninger som ikke er å betrakte som helseopplysninger.

Delprosjektene, slik de er beskrevet, faller utenfor helseforskningslovens virkeområde, jf. § 2, og kan derfor gjennomføres uten godkjenning av REK. Det er institusjonens ansvar på å sørge for at prosjektet gjennomføres på en forsvarlig måte med hensyn til for eksempel regler for taushetsplikt og personvern.

Endringer i prosjektmedarbeidere omfattes av hovedprosjektet, og er dermed fremleggingspliktig for REK. Vedtaksbrevet for denne endringen vil du motta separat.

Vi ber om at alle henvendelser sendes inn via vår saksportal: http://helseforskning.etikkom.no eller på e-post til: post@helseforskning.etikkom.no.

Vennligst oppgi vårt referansenummer i korrespondansen.

Med vennlig hilsen
Anette Solli Karlsen

Komitesekretær

post@helseforskning.etikkom.no

T: 22845522

Regional komité for medisinsk og helsefaglig forskningsetikk REK sør-øst-Norge (REK sør-øst)
http://helseforskning.etikkom.no

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK