Mastergradsoppgave

Master i tverrfaglig helse og sosialfag med fordypning i psykisk helsearbeid

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Meanings of being old, living on one`s own and suffering from incurable cancer in rural Norway. A qualitative study

Hva innebærer det å være gammel og leve alene med uhelbredelig kreft i Distrikts-Norge? En kvalitativ studie

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HØGSKOLEN I NORD-TRØNDELAG

Forord

Gjennom arbeidet med denne masteroppgaven har læringskurven vært bratt og ikke bare omfattet en studie av et fenomen der ute. Læringsprosessen har kanskje vel så mye angått min egen rolle og involvering når jeg har forsøkt å forstå, tolke og omsette bøkenes teori til praksis. Bevissthet på hvordan man selv er med på å påvirke og skape kunnskap er generelt viktig i forskningsprosessen og kanskje spesielt når man arbeider med kvalitative studier.

Da jeg som nyutdannet sykepleier i 1993 møtte praksisfeltet var jeg muligens både ambisiøs og naiv i den tro at min etiske bevissthet og gode intensjon gjorde meg godt rustet til å bistå mennesker med behov for hjelp. Etter hvert har jeg erfart at kunnskap og kompetanse har så mange dimensjoner. Teoretisk kunnskap blir fattig om den ikke utvikles og integreres i erfaringskunnskap og i selve livserfaringen som menneske. Som helsearbeidere læres vi opp til å skulle forstå og sette oss inn i pasientens situasjon. Vi skal i hurtig tempo rette empati og innlevelse mot en rekke pasienter som befinner seg i ulike sitasjoner i løpet av arbeidsdagen. Kanskje vil den empatiske evnen tape i kampen om å rekke de praktiske oppgavene som krever umiddelbar løsning? Jeg tror det er viktig å stoppe opp - og her kan den kvalitative forskningen nettopp bidra med et viktig rom for refleksjon. Den kan åpne opp for og påkalle bevissthet på et pasientperspektiv som vi kanskje mister i vår effektivitet?

Eldre mennesker har utgjort største delen av de pasienter jeg har kommet i kontakt med som sykepleier. Det generelle inntrykket er at eldre gjerne er ydmyke og ikke krever så mye på egne vegne. Ofte er det pårørende som melder deres behov. Jeg tror eldre må tildeles større oppmerksomhet i årene som kommer, ikke bare fordi de vil utgjøre en utfordring for velferdssamfunnet, men fordi de vil trenge noen som kan kjempe for deres rettigheter og verdighet.

Jeg ønsker å takke Guri Bitnes Wiik for hennes sjenerøsitet og evne til å motivere og inspirere meg i arbeidet med denne oppgaven. Stor takk skylder jeg også min veileder, Ove Hellzen som trygt har guidet metoden, stimulert til nye erkjennelser og gitt meg selvtillit.
Til slutt vil jeg takke Mari, Anna, Asgeir og Geir Arne for tålmodighet og ikke alt for store utbrudd..

Denne masteroppgaven er skrevet som en vitenskaplig artikkel. Tidsskriftet som er valgt er *European Journal of Oncology Nursing* (se vedlegg nr.1; instruksjon til forfattere). Mitt manuskript teller 6339 ord.

Innledningsvis gis en beskrivelse av artikkelens innhold og metode på norsk. Selve artikkelen; med tittelen:" Meanings of being old, living on one's own and suffering from incurable cancer in rural Norway", følger etter den norske delen.

SAMMENDRAG

Studiens hensikt: Formålet med denne studien var å frambringe meningsinnhold i den levde erfaring hos enslige, eldre med uhelbredelig kreft i Distrikts- Norge. Hvordan innvirker sykdom og behandling på det daglige liv og hva innebærer det å befinne seg i denne situasjonen?

Metode og deltakere: Datamaterialet ble innsamlet gjennom kvalitative intervju med fem eldre personer, med uhelbredelig kreft(tre kvinner og to menn i alderen 71 -79 år), som bodde alene i sine hjem i Distrikts- Norge. Alle mottok lindrende og livsforlengende cellegiftbehandling ved en poliklinikk. Fenomenologisk hermeneutisk metode ble anvendt i analysen av deres levde erfaring.

Nøkkelfunn: Fire tema ble funnet: *å utholde lidelse ved å bevare håp, å være oppmerksom på at man er alene, å leve opp til forventninger om å være en god pasient, å stå i fare for å miste identitet og verdi.* Å holde ut lidelsen innebærer å møte livstruende sykdom ved å ta tak i seg selv og tilpasse seg endrede betingelser. Møtet med helsevesenet forårsaker ytterligere påkjenning og framstår som en trussel for deres integritet og verdighet. De er på systemets nåde og befinner seg i en takknemlighetsgjeld som knebler klager og krav om bedre tilpasning.

Konklusjon: Funnene viser en kompleks situasjon hvor fysiske symptomer og følelser er sammenvevd. Ulike dimensjoner av lidelsen relatert til; - selve kreftsykdommen, -lidelse forårsaket av behandling og pleie, og lidelse knyttet til livssituasjonen forsterker hverandre. Funnene setter søkelyset på eldre kreftpasienters kamp for å opprettholde sin verdighet i den tid som gjenstår. Den sosiale og rurale konteksten ilegger helsevesenet et spesielt ansvar for å utvise oppmerksomhet og varhet i møtet med disse pasientene. Deres ressurser synes å samsvare dårlig med det ansvar som de opplever å være pålagt.

Nøkkelord: Uhelbredelig kreft, eldre, utkantstrøk, lidelse, verdighet, fenomenologisk hermeneutisk metode

ABSTRACT

Purpose of the research: The aim of this study was to gain knowledge about the lived experience of elderly people, living on their own, who suffer from incurable cancer in rural Norway. How does illness and treatment influence everyday life and what meanings can be found in these experiences?

Methods and sample: Data were collected from narrative interviews with five elderly people with incurable cancer (three women and two men, aged 71 -79), receiving outpatient and life-prolonging chemotherapy and living alone in their homes in rural Norway. Phenomenological hermeneutical approach was used to interpret the meaning of the lived experience.

Key results: Four main themes were found: *enduring by keeping the hope alive, becoming aware that you are on your own, living up to expectations of being a good patient* and *being in danger of losing identity and value.* Enduring this situation means struggling with terminal illness and facing death by gritting one`s teeth, and replacing former ways of living. The process of providing treatment causes increased distress as maintaining dignity becomes more of a challenge. Being at the mercy of the systems` schedule, indebted with gratitude, it is more difficult for the elderly persons to complain or demand adjustments.

Conclusions: These results show a complex and comprehensive situation where physical symptoms and emotions are interwoven, and describes how the ways of suffering caused by the way care is delivered, suffering related to the cancer disease and existential suffering, may increase each other's impact. The social and rural context calls for special attention as the patients lack the power to force their case through. Their comfort depends to a large extent on health professionals' sensitivity.

Keywords: Incurable cancer, elderly people, rural care, suffering, dignity, phenomenological hermeneutics

Innhold

1. INTRODUKSJON

Denne artikkelen er en del av en større studie hvor oppmerksomheten rettes mot enslige eldre i utkantstrøk som er rammet av kronisk og livstruende sykdom – deres omsorgsbehov og opplevelse av livskvalitet. En tidligere artikkel (Wiik mfl., framlagt 2011) fant at enslige, kreftrammede eldre, i rurale strøk opplever slitsomme behandlingsreiser og at deres situasjon karakteriseres av betydelig fysisk og psykisk utmattelse. Funnene indikerer at de eldre i stor grad er alene om å tilrettelegge behandling og pleie. Gjennom en ny analyse av materialet er målet å finne meningsinnhold i disse pasientenes opplevelser og utforske hva erfaringene innebærer.

Eldre representerer en stor andel av antall krefttilfeller i Norge. Tall fra det norske kreftregisteret(2008)viser at halvparten av tilfellene diagnostiseres hos personer ved 70 år eller eldre, og 40 % av alle nye tilfeller oppdages hos personer i alderen 50 til 69 år.

Med fortsatt forventet økning i levealder vil over 1000 000 innbyggere være 65 år eller eldre innen 2030. I små kommuner vil mer enn to tredeler av befolkningen være over 67 år i løpet av de neste 20 årene (Hjorthol, 2011).

Mens mye er vunnet i å gjøre kreftomsorgen bedre, har forskningen i liten grad vært opptatt av å finne ut hvordan sykdommen oppfattes av og påvirker eldre mennesker (Thomè mfl., 2003; Esbensen mfl., 2006; Blank og Bellizzi, 2008; Beck mfl., 2009; Schlairet, 2011). Eldre med kreft må betraktes som en sårbar gruppe med særskilte behov. Både kreftdiagnosen og livssituasjonen kan skape omsorgsmessige utfordringer idet aldring og sykdom forsterker hverandre(Skogen, 2006). Eldre opplever gjerne funksjonsnedsettelse og flere sykdommer samtidig, og tap av partner og venner, samt endret sosial rolle som kan influere på den psykologiske tilpasningen (McCaffery, 1994). I tillegg kan eldre i grisgrendte strøk oppleve å ha mindre tilgang til uformell pleie og omsorg fra yngre generasjoner, og dermed bli mer avhengig av offentlige tjenester (Langørgen, 2007). Tjenester som tas for gitt i urbane områder eksisterer fremdeles i begrenset grad ute i distriktene(Harris mfl., 2004). Derfor vil tilgangen på behandling og pleie ofte kompliseres med lange reiser for de som bor i utkantstrøk. I Smiths og Campbells studie(2004) medførte behandlingsreiser signifikant belastning spesielt hos de eldre kreftrammede i distriktene.

Med bakgrunn i framtidas omsorgsutfordringer lanserte den norske regjeringen høsten 2010 Samhandlingsreformen(HOD 2008 -2009) som tar sikte på å gjøre helsevesenet mer sømløst og tilpasset brukerne slik at rett behandling kan gis på rett sted og til rett tid. Blant virkemidlene står en styrket kommunehelsetjeneste og pasientrolle. Det vektlegges at

pasientens integritet og behov er selve utgangspunktet for omsorgstjenesten og at dette forplikter tjenesten, både på individ og systemplan til å vise vilje til å fange opp hva som er pasientens behov. Helsetilsynet(Sørby mfl., 2009) viser til et mangelfullt kunnskapsgrunnlag når det gjelder helsetjenester til skrøpelige eldre og oppmuntrer forskningen til å la stemmen til gamle syke pasienter og deres pårørende bli hørt.
Foruten de fysiske symptomene innebærer det å leve med alvorlig sykdom betydelig tilleggslidelse av psykologisk, sosial og eksistensiell art (Fegg mfl. 2010). Om man skal forsøke å innta pasientens perspektiv innebærer dette å forstå deres lidelse(Eriksson 1997). Dette er i følge Katie Eriksson (1997) selve omsorgens ideal – pasientens verden *er* lidelse og lindring forutsetter en forståelse for det unike menneskets erfaring.

Hensikten med denne studien er å skaffe kunnskap om den levde erfaring hos enslige eldre, med uhelbredelig kreft i Distrikts-Norge. Hvordan innvirker sykdom og behandling på deres hverdagsliv og hva innebærer opplevelsene for de eldre?

2. METODE

Kvalitativ metode anses som den mest fruktbare tilnærming for å frambringe og belyse den kunnskap jeg søker. Kvalitativ metode har sin styrke i å skaffe kunnskap om menneskelig erfaring; hvordan mennesker opplever, påvirkes av, tenker om og handler i forhold til det de erfarer(Patton, 2002).
Den kvalitative tilnærmingen bygger på en oppfatning om at kunnskap kan oppnås ved å studere verden "innenfra". Det vil si å forsøke å forstå verden fra det perspektivet informantene har. Min oppfatning er imidlertid at sanseerfaring og den "sannhet" som informantene gjengir er deres tolkning av sin livsverden. Samtidig er jeg som forskere preget av egen erfaring og livsverden og kan bare forstå deltakernes meddelelser gjennom dette filteret. Følgelig vil metoden være forankret i både fenomenologisk og hermeneutisk tradisjon, og den rommer både beskrivelse og fortolkning.
Jeg leter etter en levende kunnskap i sin naturlige sammenheng og tar utgangspunkt i det enkelte menneskets unike bidrag. Målet er ikke å generalisere, men utforske meninger og nyanser som kan utdype kvaliteter av det fenomenet som studeres(Malterud 1996).

Veien gjennom analysen vil være induktiv. Jeg har på forhånd ikke tenkt å teste data i forhold til eksisterende teori eller predefinerte kategorier.

2.1. Design

Designet er eksplorerende og intensivt(Jacobsen, 2005; Brink og Wood, 1998), og legger til rette for å søke kunnskap om nyanser og detaljer. For å skaffe innblikk i informantenes livsverden anvendes kvalitative forskningsintervju inspirert av Kvaale (2007).

2.2. Deltakere og kontekst

Deltakerne i denne studien ble rekruttert med hjelp fra personalet ved en kreftpoliklinikk tilhørende et lokalsykehus i Norge. Inklusjonskriterier var; personer med inkurabel kreftsykdom, 70 år eller eldre, under poliklinisk behandling med livsforlengende cellegift og som bodde alene og hadde minst 1 ½ time reisetid fra hjemmet til behandlingsstedet(Vedlegg nr.2).

Personalet ved poliklinikken sendte ut informasjon per post om undersøkelsen og en samtykkeerklæring til aktuelle personer(Vedlegg nr.3). De som ønsket å delta kunne kontakte forskeren om de ønsket mer informasjon eller bekrefte sin deltakelse. Sju personer ønsket opprinnelig å delta, men to personer avsluttet cellegiftbehandlingen etter den første innledende samtalen og ble derfor ikke inkludert.

Tre kvinner og to menn, i alderen 71 til 79 år(gjennomsnittsalder 76,6) deltok i undersøkelsen. Tid fra de hadde mottatt kreftdiagnosen varierte fra 6 mnd. til 9 år. På intervjutidspunktet mottok de alle livsforlengende cellegiftbehandlingen ved poliklinikken. De bodde i små kommuner(både kyst- og fjellkommuner) hvor reisetid til behandlingsstedet og tilbake til hjemmet(inkludert venting på skyss) tok fra 3 til 12 timer(gjennomsnitt 7,6 timer). Fire av de fem reiste med drosje, men de to mennene valgte etter hvert privat skyss. En av mennene måtte korrespondere med ferje og en kvinne var nødt til å ta både buss og ferje fordi hun bodde i et annet fylke. Kvinnene var enker og mennene var ugifte. Nødvendig hjelp og omsorg ble hovedsakelig utført av familie eller nabo. Noen av informantene hadde mottatt bistand fra hjemmesykepleien i korte perioder. Daglig kontakt med det sosiale nettverket bestod av kontakt med sønn eller datter for to av deltakerne, en mann hadde sin bror boende i huset ved siden av og en kvinne hadde tett kontakt med en nabo. Den femte deltakeren hadde

ingen daglig kontakt med nettverket. Med unntak av en kvinne som midlertidig overnattet hos naboen, bodde deltakerne alene i sine hjem.

2.3. Datainnsamling

Etter innhenting av skriftlig samtykke ble tidspunkt og sted for intervju avtalt. Fire av de fem ønsket at intervjuet skulle foregå hjemme hos dem, den femte ønsket ikke det og dette intervjuet foregikk på et kontor på intervjuerens arbeidssted.
Datainnsamlingen ble gjennomført med narrative intervju og en åpen spørsmålsstilling (Patton, 2002). I følge Kvaale(2007) er det i intervjusituasjonen en gjensidig avhengighet mellom mellommenneskelig interaksjon og den kunnskapen som produseres. Materialet som skapes, i siste innstans den transkriberte teksten, må derfor betraktes som et felles produkt hvor både intervjuer og respondent er forfatter. En åpen og trygg atmosfære ble tilstrebet i håp om å la informantene snakke mest mulig fritt. Samtidig var det viktig å forsikre at enkelte områder fikk oppmerksomhet for å innfri hensikten med undersøkelsen. Tre områder dannet utgangspunkt for samtalene:

- Hva mener de eldre er viktig og hva gir styrke for å mestre hverdagen?
- Erfaringer knyttet til det å leve med kreftdiagnosen
- Tanker om det å motta cellegift og erfaringer knyttet til behandlingsreisene.

Forhåndsoppstillingen av viktige emneområder bidro også til å holde oversikt og tilrettela for et mer enhetlig utgangspunkt for analysen(Vedlegg nr.4). Temaene ble introdusert i fleksibel rekkefølge slik at samtalen kunne forløpe naturlig og bekvem for den enkelte deltaker. Personene ble oppmuntret til å fortelle om spesielle situasjoner og reflektere over tanker, følelser og handlinger(Drew 1993). Intervjueren forsøkte å avbryte minst mulig, og forfulgte ikke tema som ble oppfattet som for nærgående eller når informanten signaliserte at det var ting han eller hun ikke ønsket å utdype. Intervjuene varte fra 55 -125 minutter og alle informantene godkjente lydopptak. Disse lydopptakene ble transkribert umiddelbart etter intervjuene og observasjonsnotater ble nedskrevet under samtalene.

3. ETIKK

Denne studien er gjennomført med godkjenning fra Regional Etisk komité- Nord(No. 4.2007.1149)(Vedlegg nr.5) og databehandling og personvern er i tillegg sikret gjennom føringer fra Norsk Samfunnsvitenskaplig Datatjeneste(NSD)(Vedlegg nr.6). Et overgripende etisk prinsipp er at forskningens formål skal ha en verdi utenfor seg selv og forskerens krets(Ingierd, 2010).

Forskeren har derfor et etisk ansvar både for de personene forskningen angår(direkte eller indirekte) og for måten metoden anvendes på i innhenting av kunnskap(vitenskaplig redelighet, saklighet, åpenhet). Viktige etiske refleksjoner angår samtykke, konfidensialitet og konsekvenser.

3.1. Samtykke

Et viktig prinsipp i studien er frivillig deltakelse. Når rekruttering skjer via en instans eller personer som deltakerne kan tenkes å ha et avhengighetsforhold til, kan frivillighet problematiseres. I denne undersøkelsen sendte poliklinikken informasjon per post til aktuelle personer og det var opp til deltakerne å ta kontakt med forskeren hvis de ønsket å la seg intervjue. Personalet ved poliklinikken fikk slik ingen informasjon om hvem som ønsket eller ikke ønsket å delta. Deltakerne fikk både skriftlig og muntlig informasjon om studiens formål, databehandling og sikring av konfidensialitet. Informasjonen angikk også eventuelle negative konsekvenser og det ble opplyst om muligheten til å trekke seg fra studien.

3.2. Konfidensialitet

Faren for at enkeltpersoner kan identifiseres øker jo mindre utvalget er. Detaljeringsgrad i presentasjonen av funnene er derfor vurdert og jeg benytter verken navn eller geografisk angivelser. For å sikre personvernet ble materialet behandlet i tråd med retningslinjer satt av REK- Nord og NSD.

3.3. Konsekvenser

Formålet i denne undersøkelsen er å framskaffe kunnskap om en sårbar gruppes livssituasjon for å avdekke omsorgsbehov. Det kan knyttes betenkeligheter til å utsette mennesker, som allerede befinner seg en utsatt posisjon, for den eventuelle belastning deltakelse vil medføre. Etiske forskningskomiteer legger derfor vekt på å skåne mennesker for psykiske belastninger, men også fysiske begrensninger vurderes. I denne undersøkelsen var deltakerne selv i stand til

å ta stilling til deltakelse og de uttrykte underveis opplevelse av mening og av å være til nytte selv om funnene ikke ville komme dem selv til gode.
Når mennesker lar seg intervjue vil de alltid blottstille noe av seg selv, og forskeren må utvise varhet for og være oppmerksom på mulige negative konsekvenser. I denne studien ble det etablert en beredskap for eventuelle behov av somatisk, psykisk eller praktisk art som kunne dukke opp som en følge av deltakelse.

Etisk bevissthet som forsker er vesentlig gjennom hele prosessen. Når det kommer til tolkning og rapportering vil det også være farer: Hvor mye overskrides deltakernes selvforståelse? Er det risiko for at jeg overanalyserer eller ikke er trofast i bruken av deres utsagn? Kan direkte sitering virke stigmatiserende når språket blir gjengitt i den muntlige og ofte ustrukturerte form det ble sagt?

4. ANALYSE

Analysen forener fenomenologisk filosofi med hermeneutisk tolkning i en dialektisk prosess(Ricoeur, 1991). Metoden ble utviklet til anvendelse for sykepleieforskning gjennom et samarbeid mellom universitetene i Umeå og i Tromsø(Lindseth og Nordberg 2004). Den er anvendt i flere kvalitative studier som Rasmussen, Sandman og Norberg (1997) og Skovdahl, Kihlgren and Kihlgren (2003).
Den fenomenologiske tradisjon argumenterer for å la informantene synliggjøre sin verden og beskrive den med egne ord slik den fremstår før vi begynner å reflektere eller teoretisere over den. I følge Edmund Husserl, som anses som den moderne fenomenologiens grunnlegger, er verden *henvist til subjektet for å framtre*(Thornquist 2003). Det finnes en livsverden som eksisterer forut for enhver refleksjon og denne kan betraktes fra konkrete og situasjonsbestemte gjengivelser fra de som erfarer(sanser)den. Husserl hevder at mennesket alltid har sin oppmerksomhet eller bevissthet rettet mot noe, og fenomenologiens oppgave er å undersøke fenomener ut fra den betydning de har i vår bevissthet. Målet er å nå fram til essenser ved å gå fra en ren beskrivelse til å søke etter fenomeners allmenne vesen(Brinkmann og Tanggaard 2010). Tilstedeværelse av essenser er en nødvendighet – vi må ha et felles språk for å kunne kommunisere i en felles verden(Lindseth og Nordberg 2004). En undersøkelse av et fenomens vesen kan eksempelvis gjøres ved å benytte fantasi og tenke fritt om et fenomens mulige former, og essensen vil da ligge bak disse variasjonene(Brinkmann og Tanggaard 2010). Dette perspektivet kommer til nytte i analysens

første fase som er å foreta en naiv lesning. På bakgrunn av å ha lest intervjumaterialet gjentatte ganger og dannet meg et første helhetsinntrykk formuleres en forståelse av essensen i informantenes levde erfaring(Lindseth og Nordberg 2004). Lindseth og Nordberg(2004) hevder imidlertid at det å begripe essensen i et fenomen ikke er så liketil som Husserl kan ha ment. De framhever betydningen av å medtenke hvordan vi som forskere er med på å konstruere virkeligheten og at virkelighet som formidles via nedskrevne historier nødvendigvis må tolkes for å forstås. Denne tilnærmingen tror derfor ikke på ren fenomenologi, men på en kombinasjon med hermeneutikk. Hermeneutikken finner det umulig å sette egen forforståelse i parentes – vi er alle en del av verden og vår forståelse av verden vil alltid være en funksjon av vår involvering i den (Larkin et.al. 2006).

Hermeneutikken tar utgangspunkt i fortolkning av tekst. I følge Ricouer (ref.i; Thompson 1994) er språket et medium til fortolkning av vårt indre liv, det følger bestemte regler, formidler erfaringer og historier. Idet tale nedtegnes som tekst må teksten betraktes som en selvstendig enhet – den er løsrevet fra forfatteren og det som skjer i tolkningen av teksten skjer mellom leseren og tekstens diskurs(Thompson 1994). Ricouer mener derfor at det er en villfarelse å tro at tolkningen må søke å forstå intensjonen til forfatteren bak teksten. Selve tolkningen innebærer både forståelse og forklaring i Ricoeurs verden. Tolkning er å begripe den verdenen som åpner seg *foran* teksten. Det som må fortolkes i en tekst er en mulig verden som man kan ta del i og denne verden framsettes som den mest mulige.

Analysens neste trinn er en strukturanalyse som innebærer å dele opp teksten i meningsenheter guidet av den naive forståelsen og studiens hensikt. Dette trinnet anses som den metodiske delen av fortolkningen og blir en måte å bekrefte eller avkrefte den naive forståelsen på (Lindseth og Nordberg 2004).

Meningsenhetene trekkes ut av konteksten og blir gjenstand for vurdering og refleksjon. I denne behandlingen av teksten er språkets struktur og bruk interessant(for eksempel metaforer, bruk av personlige pronomen). Strukturanalysen kan utformes ulikt. Målet er å finne tema som kan ses som beholdere for meningsenhetene og fange opp essensielle meninger om den levde erfaring.

Ricoeur beskriver den strukturelle analysen som en "forklaring" – den viser den interne og avhengige relasjonen som skaper en statistikk i teksten. Dette trinnet anses som nødvendig for å bringe den naive forståelsen til en kritisk tolkning – fra en overflatisk til en dypere tolkning(Thompson, 1994). Prosessen er ikke lineær, men beveger seg fram og tilbake og følger på mange vis den hermeneutiske spiral etter hvert som de dekontekstualiserte

meningsenhetene abstraheres og kondenseres for igjen rekontekstualiseres i en bredere ramme og vinner ny innsikt.

Til slutt tolkes teksten igjen som en helhet i lys av den naive forståelsen, strukturanalysen, vår forforståelse og den teoretiske rammen.

Med tolkning oppnås dermed det konkrete utbytte av sammenstilling og fornying og denne prosessen vil involvere både *forklaring* og *forståelse*(Ricoeur 1991). Dette bidraget fra Ricoeur innehar etter min mening en mulighet til å gjøre analysen synlig og rimelig – den blir mer transparent og kan gjøres tilgjengelig for andres kritiske vurdering.

5. RESULTATER

Resultatene av analysen presenters i naiv forståelse, strukturanalyse og tolket helhet

5.1. Naiv forståelse

Informantene beskriver en utmattende tilværelse hvor de følelsesmessig slites mellom håp og fortvilelse. De opplever å være alene og må stole på hjelp fra naboer og slektninger. Den lokale helsetjenesten framstår som lite til hjelp og de føler seg ofte avvist eller neglisjert. Å motta cellegift vekker tillit og forhåpninger, men de settes samtidig i en takknemlighetsgjeld fordi denne behandlingen ikke oppfattes som en selvfølge når en tar deres alder i betraktning. De ønsker ikke å framstå som krevende eller klagende. Organisering av prøver og behandling(spesielt reisene til og fra behandling) er belastende og medfører stress og bekymring. Samtidig må de forholde seg til et fysisk forfall og at slutten på livet er nær. Lidelsen er åpenbar og energitapet stort i den daglige utholdelse. Lite krefter er igjen til aktiviteter som før gjorde livet verdt å leve.

5.2. Strukturanalyse

Analysen endte opp i fire hovedtema som belyser hva den levde erfaring innebærer. Noen av disse temaene innehar også nyanser som beskrives gjennom subtema (se Vedlegg nr.7 over analyseprosessen).

5.2.1. Å utholde lidelse ved å bevare håp

Subtema: tillit til kreftpoliklinikkens kompetanse, mestre motstridende følelser, drømme og planlegge.

Håpet og viljen til å leve står sterkt i de eldres historier - de viser ikke tegn til å ha gitt opp. Med cellegiften oppfatter de at de låner seg tid og dette nærer håp og krefter. Håpet blir et aktivt valg. Det er synlig i tilliten til sykehusets ekspertise og er også en drivkraft i mestring av kaotiske følelser og forsøk på å skape en framtid å strekke seg etter.

5.2.2. Å bli oppmerksom på at man er alene

Subtema: Å navigere alene. De eldre er vant til å greie seg selv og viser en tydelig stolthet når de forteller om hverdagslivet. Samtidig utgjør sykdom og funksjonssvikt en trussel mot denne uavhengigheten og de innser at de kan ha eller få behov for hjelp. Engstelsen for å være til bry for andre er uttalt. Især gjelder dette familien, men de ønsker heller ikke å belaste den offentlige hjelpen. Fra hjelpeapparatet oppfatter de tydelige anmodninger om å være selvstendige og de bruker mye tid og krefter på å bestille timer ved legekontor og planlegge behandlingsreisene. Dette etterlater frustrasjon, en følelse av unødig ressursbruk, og en erkjennelse av bare å ha seg selv å stole på.

5.2.3. Å leve opp til forventninger om å være en god pasient

Subtema: å ha lite kontroll, å unngå å være til bry.

En tradisjonell maktbalanse mellom pasient og helsevesen(hjelper) gjenspeiler seg i intervjuene. Informantenes uttalelser synliggjør en takknemlighet som forplikter tilpasning og stimulerer til underdanighet. Forventninger om å utvise selvstendighet og egenomsorg utfordres imidlertid av manglende kontroll og forutsigbarhet. Det blir vanskelig å stille egne krav og vite hvordan man skal opptre.

5.2.4. Å stå i fare for å miste identitet og verdi

Subtema: å være i forfall, miste verdighet, miste kontinuitet. Informantene beskriver en innskrenket livsverden som er preget av både fysisk og psykisk forfall. Uverdigheten er svært iøynefallende og noen assosierer seg med søppel og sier at de føler seg verdiløse. Det fysiske forfallet knyttet til kreftsykdommen og cellegiftbehandlingen er påtagelig og alle er opptatt av vektreduksjon og kronisk slapphet. De må forsake aktiviteter og opplevelser og de kjemper for å bevare et bilde av seg selv som de kan leve med. Lidelsen som synliggjøres er eksistensiell.

5.3. Tolket helhet

Fortolkningen av den levde erfaring indikerer at både livskvalitet og livet selv er på risk. Å hold ut lidelsen innebærer å møte livstruende sykdom ved å ta tak i seg selv og tilpasse seg endrede betingelser. Cellegiftbehandlingen representerer hovedåren til håpet, selv om den innebærer både fysisk og psykisk elendighet. Møtet med helsevesenet forårsaker ytterligere påkjenning og framstår som en trussel for deres integritet og verdighet. De er i stor grad overlatt til egen omsorg uten å ha den nødvendige kontroll og mulighet til samhandling. De befinner seg på systemets nåde og i en takknemlighetsgjeld som knebler klager og krav om bedre tilpasning. Det synes å være et misforhold mellom de eldres behov og den hjelp som gis, eller kanskje mest i *måten* hjelpen gis på.

Den verden av lidelse som framkommer i historiene kan ses i lys av Katie Erikssons lidelses teori. Eriksson(1995)ser pasientens lidelse i forhold til: - sykdommens fysiske konsekvenser, - lidelse om kan være en følge av behandling og pleie(pleielidelsen), og selve livssituasjonens lidelse.

Lidelsen forårsaket av behandling og pleie er det mest iøynefallende funnet i denne studien og kommer til uttrykk i temaene; *å være oppmerksom på at man er alene*, *å leve opp til forventninger om å være en god pasient* og *stå i fare for å miste identitet og verdi*. Som en kontrast i dette bildet, og kanskje et paradoks, står informantenes håp. Håpet gjør lidelsen utholdelig og blir over alt viktig å holde fast ved. Foruten å være et uttrykk for selve viljen til å fortsette å leve innehar håpet også et behov for anerkjennelse og verdighet. Dette behovet synes lite påaktet og blir ofte krenket i stedet for møtt.

6. KONKLUSJON

For mennesket som står i lidelsen er opplevelsen kompleks og den teoretiske inndeling har ikke til hensikt å skjule det sammensatte bildet, men snarere tydeliggjøre en lidelse som er unødvendig og som kan nedkjempes.

Funnene setter søkelyset på eldre kreftpasienters kamp for å opprettholde sin verdighet i den tid som gjenstår. Den sosiale og rurale konteksten ilegger helsevesenet et spesielt ansvar for å

utvise oppmerksomhet og varhet i møtet med disse pasientene. Deres ressurser synes å samsvare dårlig med det ansvar som de opplever å være pålagt.

7. BETRAKTNINGER OM METODEN

Hva har min metode gitt relevant eller gyldig kunnskap om?

Når jeg skal bedømme hvorvidt min metode har vært relevant og hvilken gyldig innsikt som er vunnet må hele forskningsprosessen tas i betraktning. For det første kan formuleringen av problemstillingen vurderes. Målet var å forstå hva det innebærer for informantene, enslige, eldre med uhelbredelig kreft i utkant Norge, å oppleve det de opplever. I forskningsterminologien omtales dette nivået som den levde erfaring og inneholder et abstraksjonsnivå som strekker seg utover det rent opplevelsesmessige aspektet. Dette indikerer allerede at hensikten er å skaffe kunnskap som krever refleksjon – en kunnskap som kanskje ikke er så lett tilgjengelig, verken for forskeren eller de som innehar den(lever i den). Valget av metode falt på en fenomenologisk hermeneutisk tilnærming fordi jeg tror at bildet av informantens livsverden konstrueres både av informanten selv, av interaksjonen i intervjusituasjonen og den bearbeiding som skjer når forskeren, med sin livsverden, møter produktet – datamaterialet i form av tekst. Som Lindseth og Nordberg(2004) hevder kan fenomenologien, i tradisjonell forstand, vanskelig stå alene i et forsøk på å finne "sannheten" om verden. Vi er alle i konstant interaksjon med verden og former den i vårt bilde. Og den "egentlige verden" eller "egentlige mening" er noe som ikke kan finnes, men som kan skapes (Kvaale 2006). Ved å anvende hermeneutikkens filosofi vil nettopp bildet av verden *skapes* fordi vi må medregne vår egen innblanding og forforståelse som både vil være bevisst og ubevisst.

Hvem forskeren er og hvilken bagasje han/hun har med vil være avgjørende for forståelsen. I arbeidet med å analysere dette materialet har jeg ofte tatt meg selv i å tro at den "egentlige" mening kan finnes og dette har skapt en uro; hva mente egentlig informanten med dette utsagnet? For å forstå hevdes det at vi er avhengig av de essensielle meningene(Lindseth og Nordberg 2004). Disse meningene formidles via språket – ordene vi anvender og assosierer med. Igjen legges det opp til muligheter for tvil, fordi ordene informantene bruker har en betydning i deres verden og kanskje en annen i min verden? Etter hvert har jeg innsett at jeg som forsker, eller som menneske, aldri kan forstå identisk det den andre gjør. Og om jeg skal oppfylle mine forpliktelser i å være tro mot data og informantenes meddelelser, handler dette

heller om evne til å redegjøre for stegene i analysen; vise rimeligheten for at funn ble som de ble.

Ricouer (ref. i: Thompson 1994) sier at teksten(datamaterialet) må betraktes som adskilt fra forfatteren. Og med Ricoeurs tanker opplever jeg å kunne rettferdiggjøre min tolkning. Analysen er en dialog med teksten, eller tekstens diskurs – og ikke med informantene i seg selv. Mine funn er derfor et produkt av den forståelse jeg kan oppnå fra teksten, egen forforståelse og bakgrunn, og den teoretiske ramme jeg har valgt. Ved å oppdele analysen i tre steg blir tolkningen tydeliggjort(og forklart ifølge Ricoeur(Thompson 1994)) og den blir også i større grad kommuniserbar og kan etterprøves.

Kvalitative studier er mer opptatt av å oppnå dyp forståelse av unike individer i en spesiell kontekst enn å generere kunnskap som kan generaliseres og være representativ(Patton, 2002). Det vil imidlertid være ønskelig, og med en fenomenologisk antakelse være en mulighet, for at analysen har synliggjort essensens vesen – funnet det generelle i det spesielle, det gjenkjennbare.

> *The trouble with generalizations is that they don't apply to particulars.*
> (Lincoln og Guba 1985:110 I Patton, 2002 s.581)

Problemet med generalisering kan forstås å være tilstede både om man trekker slutninger fra mange individer til få, eller fra få til mange. Mennesker og menneskelige fenomener er kontekstuelle og om kunnskap kan sies å ha overførbarhet vil avhenge av den situasjon eller forhold kunnskapen skal relateres til.

Kvalitativ forskning kan tilby perspektiver og oppfordre til dialog mellom perspektivene uten at det framsettes sannheter eller kausale forklaringer (Patton, 2002). Resultatene i denne studien må derfor ses som mitt bidrag til å gi et perspektiv på hva det å være gammel, enslig og uhelbredelig kreftsyk i utkantstrøk kan innebære. Målet er å berøre, påkalle oppmerksomhet og stimulere til refleksjon. I min verden tilfører den kvalitative forskningen kunnskapsfeltet en særegen og nødvendig kvalitet; vi har behov for både å bli opplyst og berørt for å forstå mer, stille nye spørsmål og kanskje handle annerledes.

Som en troverdighetssjekk er selve framgangsmåten i analysen og resultatene i denne studien vurdert av to veiledere/analytikere. Ved at flere øyne ser på materialet og bearbeidningen av det, kan skjevheter som en mulig følge av den hermeneutiske prosessen korrigeres. Hvorvidt sannhetsinnholdet i funnene styrkes ved at flest mulig er enig om noe kan diskuteres, men redeligheten i det vitenskaplige arbeidet blir på denne måten kontrollert.

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Where the family name may be ambiguous (e.g., a double name), please indicate this clearly. Present the Authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the Author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name, and, if available, the e-mail address of each Author.

Corresponding Author
Clearly indicate who is willing to handle correspondence at all stages of refereeing and publication, also post-publication. **Ensure that telephone and fax numbers (with country and area code) are provided in addition to the e-mail address and the complete postal address.**

Present/permanent address
If an Author has moved since the work described in the article was done, or was visiting at the time, a "Present address" (or "Permanent address") may be indicated as a footnote to that Author's name. The address at which the Author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

Abstract
A concise and factual abstract is required (maximum length 250 words). The abstract must be structured and should state the following: a) Purpose of the research; b) methods and sample; c) key results, and d) conclusions. An abstract is often presented separate from the article, so it must be able to stand alone. Abstracts should not include any references.

Keywords
Immediately after the abstract, provide a maximum of ten keywords, avoiding general and plural terms and multiple concepts (avoid, for example, "and", "of"). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

Abbreviations
Define abbreviations that are not standard in this field at their first occurrence in the article: in the abstract but also in the main text after it. Ensure consistency of abbreviations throughout the article.

Subdivision of the article
Divide your article into clearly defined sections. Each subsection is given a brief heading. Each heading should appear on its own separate line. Subsections should be used as much as possible when cross-referencing text: refer to the subsection by heading as opposed to simply "the text".

Acknowledgements
All contributors who do not meet the criteria for authorship as defined above should be listed in an acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who provided only general support. Authors should disclose whether they had any writing assistance and identify the entity that paid for this assistance.

Conflict of interest
At the end of the text, under a subheading "Conflict of Interest Statement" all authors must disclose any financial and personal relationships with other people or organisations that could inappropriately influence (bias) their work. Examples of potential conflicts of interest include employment, consultancies, stock ownership, honoraria, paid expert testimony, patent applications/registrations, and grants or other funding. If there are no conflicts of interest please state "None declared".

Role of the funding source
All sources of funding should be declared as an acknowledgement at the end of the text. Authors should declare the role of study sponsors, if any, in the study design, in the collection, analysis and interpretation of data; in the writing of the manuscript; and in the decision to submit the manuscript for publication. If the study sponsors had no such involvement, the authors should so state.

Figure captions, tables, figures, schemes
Present these, in this order, at the end of the article. They are described in more detail below. High-resolution graphics files must always be provided separate from the main text file (see Preparation of illustrations).

Footnotes
Footnotes should be used sparingly. Number them consecutively throughout the article, using superscript Arabic numbers. Many wordprocessors build footnotes into the text, and this feature may be used. Should this not be the case, indicate the position of footnotes in the text and present the footnotes themselves on a separate sheet at the end of the article. Do not include footnotes in the Reference list.
Table footnotes: indicate each footnote in a table with a superscript lowercase letter.

Tables
Number tables consecutively in accordance with their appearance in the text. Place footnotes to tables below the table body and indicate them with superscript lowercase letters. Avoid vertical rules. Be sparing in the use of tables and ensure that the data presented in tables do not duplicate results described elsewhere in the article.

Nomenclature and units
Follow internationally accepted rules and conventions: use the international system of units (SI). If other quantities are mentioned, give their equivalent in SI.

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References

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Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in

the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either "Unpublished results" or "Personal communication" Citation of a reference as "in press" implies that the item has been accepted for publication.

Citing and listing of web references
As a minimum, the full URL should be given. Any further information, if known (Author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

All citations in the text should refer to:
1. *Single Author:* the Author's name (without initials, unless there is ambiguity) and the year of publication;
2. *Two Authors:* both Authors' names and the year of publication;
3. *Three or more Authors:* first Author's name followed by "et al." and the year of publication.

Citations may be made directly (or parenthetically). Groups of references should be listed first alphabetically, then chronologically.
Examples: "as demonstrated (Allan, 1996a, 1996b, 1999; Allan and Jones, 1995). Kramer et al. (2000) have recently shown ...."

List: References should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same Author(s) in the same year must be identified by the letters "a", "b", "c", etc., placed after the year of publication. If the reference is to a journal, the journal title should be listed in full and not abbreviated.
Examples:
Reference to a journal publication:
Van der Geer, J., Hanraads, J.A.J., Lupton, R.A., 2000. The art of writing a scientific article. Journal of Scientific Communication 163, 51-59.
Reference to a book:
Strunk Jr., W., White, E.B., 1979. The Elements of Style, third ed. Macmillan, New York.
Reference to a chapter in an edited book:
Mettam, G.R., Adams, L.B., 1999. How to prepare an electronic version of your article, in: Jones, B.S., Smith , R.Z. (Eds.), Introduction to the Electronic Age. E-Publishing Inc., New York, pp. 281-304.

Use of the Digital Object Identifier (DOI)

The digital object identifier (DOI) may be used to cite and link to electronic documents. The DOI consists of a unique alpha-numeric character string which is assigned to a document by the publisher upon the initial electronic publication. The assigned DOI never changes. Therefore, it is an ideal medium for citing a document, particularly 'Articles in Press' because they have not yet received their full bibliographic information.

The correct format for citing a DOI is shown as follows (example taken from a document in the journal *Physics Letters B*):
doi:10.1016/j.physletb.2003.10.071

When you use the DOI to create URL hyperlinks to documents on the web, they are

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• Supply embedded graphics in your wordprocessor (spreadsheet, presentation) document;
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The lettering and symbols, as well as other details, should have proportionate dimensions, so as not to become illegible or unclear after possible reduction; in general, the figures should be designed for a reduction factor of two to three. The degree of reduction will be determined by the Publisher. Illustrations will not be enlarged. Consider the page format of the journal when designing the illustrations.
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Remove non-essential areas of a photograph. Do not mount photographs unless they form part of a composite figure. Where necessary, insert a scale bar in the illustration (not below it), as opposed to giving a magnification factor in the legend.

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Elsevier will do everything possible to get your article corrected and published as quickly and accurately as possible. In order to do this we need your help. When you receive the (PDF) proof of your article for correction, it is important to ensure that all of your corrections are sent back to us in one communication. Subsequent corrections will not be possible, so please ensure your first sending is complete. Note that this does not mean you have any less time to make your corrections, just that only one set of corrections will be accepted.

VEDLEGG NR.2: INKLUSJONSKRITERIER

Kriterier for utvalget:

- Utvalget rekrutteres fra en kreftpoliklinikken.
- Informantene s plukkes fra noen utvalgte distrikts-kommuner
- Informantene skal bo i en kommune med minst 1 ½ times reise til der det aktuelle behandlingsstedet er etablert.
- Over 70 år.
- Bor alene i eget hjem.
- Får palliativ behandling (livsforlengende) med cellegift.
- Pasientens kreftdiagnose skal ikke være ny-diagnotisert.
- Tar sikte på at utvalget fordeles ca 50 / 50 mellom menn og kvinner.
- De fire vanligste kreft typene som finnes er lungekreft, prostatakreft, brystkreft og mage/tarm kreft (Kreftregisteret 2008). Det er derfor naturlig å tenke seg at utvalget vil være rammet av en eller flere av disse diagnosene. Imidlertid kan det ikke utelukkes at utvalget kan ha en annen kreft type enn det som er nevnt. For studien er det ikke hviken diagnose utvalget har, som er av overordnet betydning. Bakgrunn for de valgte kriteriene for utvalget er utfordringer knyttet til livsforlengende behandling og livskvalitet.

VEDLEGG NR.3: INFORMASJON OG SAMTYKKE

Forespørsel om å delta i en vitenskapelig undersøkelse

Dette er en forespørsel om du er villig til å delta i et vitenskapelig prosjekt og la deg intervjue. Prosjektets tittel er "Eldre med Kreft ".

BAKGRUNN OG HENSIKT

Mye forskning er blitt gjort om hvordan cellegiftbehandlingen virker, men det har vært lite fokus på hvordan det påvirker hverdagen til den som får denne behandlingen, spesielt eldre over 70 år. Derfor er det ønskelig å undersøke mer om de *utfordringene eldre* kreftrammede står oppe i, og dine erfaringer og syn på emnet er viktig.

Dette er en forskningsstudie for å se hvordan det er å leve med kreft i eldre år, og skal være et ledd i en større kartlegging.

HVA INNEBÆRER STUDIEN?

Undertegnede har forespurt Kreftpoliklinikken om å hjelpe til med å skaffe aktuelle personer som kan forespørres om å bli med på et intervju om hvordan det er å leve med kreft i eldre år. På grunn av Kreftpoliklinikkens taushetsplikt, blir det de som sender denne forespørselen. Prosjektansvarlig vet ikke hvem som får forespørsler, og Kreftpoliklinikken vet ikke hvem som svarer. På denne måten vet ikke Kreftpoliklinikken hvem som blir med i prosjektet, og intervjuer vet ikke hvem som forespørres. Taushetsplikten er dermed ivaretatt. Utover dette har ikke Kreftpoliklinikken mer med prosjektet å gjøre.

Intervjuer er spesialsykepleier, og har lang erfaring i arbeidet mot de utfordringer som kreftpasienter står oppe i. Intervjuet skal foregå nærmest som en samtale om emnet, og intervjuer har bare noen få spørsmål som utgangspunkt. Det er du som sitter med kunnskapen om dine opplevelser med sykdommen. En slik samtale vil vare en til to timer. Det kan hende det at vi trenger litt mer tid, og det er fullt mulig å avbryte tidligere og forlenge det ytterligere. Du og intervjuer blir enige om hvor intervjuet skal foregå. Det kan være hjemme hos deg eller et annet sted vi blir enige om. Selve intervjuet tar jeg opp på lydbånd, slik at jeg får med meg alt du sier.

Mulige fordeler og ulemper

Hvis du i forbindelse med intervjuet får behov for hjelp, vil jeg som intervjuer bistå med å formidle det til hjelpeapparatet, enten om det er av medisinsk eller praktisk art. Dette er avtalt med Kreftpoliklinikken og medisinsk ansvarlig.

Hva skjer med informasjonen om deg?

Lydbåndet med intervjuet, vil bli skrevet ut og så bli slettet innen 30 dager etter intervjuet. Ingenting skal kunne gjenkjennes eller bli gjengitt slik at informasjonen skal kunne førs tilbake til deg. Sensitive personopplysninger blir låst inn i et arkivskap av undertegnede. Resten av innsamlede opplysninger blir lagret på jobb PC, med privat brukernavn og passord. Det er bare du og jeg som intervjuer som kjenner til vår samtale.

Prosjektet er godkjent av Regional Komite` for Medisinsk og helsefaglig Forskningsetikk.

Frivillig deltakelse

Det er frivillig å delta i studien. Dersom du ønsker å delta, undertegner du samtykkeerklæringen som følger med. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for din videre behandling.

Rett til innsyn og sletting av opplysninger om deg

Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Dersom du nå eller i ettertid lurer på noe, kan du ta kontakt med undertegnede.

Svarer du ja til å delta, kan du fylle ut navn, adresse og telefonnummer på samtykkeerklæringen, og legge det i vedlagte frankerte konvolutt og sende det i posten. Du kan også kontakte meg på telefon hvis du ønsker det.

Vennlig hilsen

_____

Guri Bitnes Wiik
Intervjuer / prosjektleder

Høgskolen i Nord-Trøndelag

Finn Christiansensv. 1
7800 NAMSOS

Mobil 412 74 894

Samtykke til deltakelse i studien "Eldre med Kreft"

Jeg har lest informasjonsskrivet og har hatt anledning til å stille spørsmål. Jeg er villig til å delta i studien.

Sted:_____

Dato:_____

Underskrift:_____

Telefon:_____

VEDLEGG NR.4: INTERVJUGUIDE

Innledningsspørsmål:

- *Kan du fortelle meg hva som er viktig for deg i livet ditt, og som gir deg styrke til å greie dagen?*

Spørsmål knyttet til hverdagen:

1A: *Fortell om hvordan det er å leve med kreft.*

1B: *Fortell om hvordan kreften påvirker hverdagen din.*

Spørsmål knyttet til behandlingen:

2A: *Fortell om dine tanker og erfaringer om hvordan du opplever behandlingen.*

2B: *Fortell om en reise til behandling.*

Spørsmål knyttet til oppfølging:

3A: *Fortell om dine tanker og erfaringer om hjelpen du har fått.*

3B. *Hvilke tanker og erfaringer har du om informasjonen du har fått*

Tilleggsspørsmål til alle spørsmålene:

Fortell om en/flere situasjoner i hverdagen som fungerer bra for deg, tross sykdommen

Fortell om en/flere situasjoner i hverdagen som ikke fungerer bra for deg

VEDLEGG NR.5: NYE ANALYSER PÅ ANONYMISERT MATERIALE

Fra: Gaare Monika Rydland [mailto:monika.gaare@uit.no] **På vegne av** REK NORD
Sendt: 1. juni 2010 11:16
Til: Hellzen Ove
Emne: RE: utøkad information angående REF: P REK NORD 128/2007 ELDRE OG KREFT I BY OG LAND - EN KVALITATIV METODE

Vi viser til nedenstående e-post av 27.05.2010 med vedlegg.

Forskning på anonyme data er ikke fremleggingspliktig for REK. Fra studien "Når den enslige eldre i distrikts-Norge er rammet av uhelbredelig kreft - en kvalitativ studie"er det et forholdsvis lite datamateriale på en spesiell gruppe pasienter ved HF Nord Trøndelag og HF Sykehuset Innlandet som ønskes analysert.

Komiteen legger til grunn at materialet faktisk er anonymisert og har ingen innvendinger mot at det gjøres nye analyser av dette anonymiserte materialet.

Vennlig hilsen
Monika Rydland Gaare
Førstekonsulent
Regional komité for medisinsk og helsefaglig forskningsetikk, Nord-Norge (REK Nord)
TANN-bygget, Universitetet i Tromsø, 9037 Tromsø
rek-nord@fagmed.uit.no
telefon 776 20756

VEDLEGG NR. 6: GODKJENNING NSD

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

NSD

Harald Hårfagres gate 29
N-5007 Bergen
Norway
Tel: +47-55 58 21 17
Fax: +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr. 985 321 884

Guri Bitnes Wiik
Den norske kreftforening
Postboks 4 Sentrum
0101 OSLO

Vår dato: 29.06.2007 Vår ref: 16867/KS Deres dato: Deres ref:

TILRÅDING AV BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 08.05.2007. Meldingen gjelder prosjektet:

16867	*Eldre og kreft i by og land - en kvalitativ studie*
Behandlingsansvarlig	*Den norske kreftforening, ved institusjonens øverste leder*
Daglig ansvarlig	*Guri Bitnes Wiik*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven/-helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/endringsskjema. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://www.nsd.uib.no/personvern/register/

Personvernombudet vil ved prosjektets avslutning, 31.12.2009, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Vigdis Namtvedt Kvalheim

Katrine Utaaker Segadal

Kontaktperson:Katrine Utaaker Segadal tlf: 55 58 35 42

Vedlegg: Prosjektvurdering

Avdelingskontorer / District Offices:
OSLO: NSD. Universitetet i Oslo, Postboks 1055 Blindern, 0316 Oslo. Tel: +47-22 85 52 11. nsd@uio.no
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TROMSØ: NSD. SVF, Universitetet i Tromsø, 9037 Tromsø. Tel: +47-77 64 43 36. nsdmaa@sv.uit.no

VEDLEGG NR.7: ANALYSEPROSESS - EKSEMPLER

Tab.1: Eksempler på meningsenheter i teksten, kondenserte meningsenheter, sub-tema (der de finnes), og tema.

Meningsenheter fra teksten	Kondenserte meningsenheter	Sub- tema	Tema
Legen sa jo at jeg kunne få et år ekstra når jeg tok denne giften// ..han sa at han fikk kjøpt seg mer tid. Det var godt sagt det... //Mora mi døde også av kreft i magen. Hun hadde det ikke bra... stakkars. Det var ikke så god hjelp den gang veit du.	Legen sa at jeg kunne få et år ekstra – kjøpe meg mer tid hvis jeg tok denne giften. I dag finnes det god hjelp.		Å utholde lidelse ved å bevare håp
Ja, de på sykehuset ordner opp med alt... med medisin og sånt. Så der kan jeg spørre og klage (ler)... Det syns jeg er greit.// De er flinke til å sette seg ned på kreftpoliklinikken når de har tid// Men jeg må jo fortsette... for tar jeg ikke behandlingen, så blir jeg ikke bra	De ordner alt på sykehuset. De har kompetanse og medisiner. De tar vare på meg.	tillit til poliklinikkens kompetanse	Å utholde lidelse ved å bevare håp
Hvis noen har sagt til meg at nå er du frisk så vet jeg sannelig ikke hvordan jeg har reagert. Det høres rart ut, men slik føles det. Men så går du der hele tiden og tenker på hva skal du få høre nå. Ja det er mye spenning, og du blir ... (sukk) sånn der.// Jeg spør minst mulig, jeg ønsker ikke å høre det negative, det får jeg ta senere. Nå vil jeg høre bare det positive. Da vokser jeg og får styrke	Jeg går i en konstant spenning og forbereder meg på det verste. Jeg unngår å stille så mange spørsmål – vil bare høre det positive, det gjør meg sterkere	mestre motstridende følelser	Å utholde lidelse ved å bevare håp

Jeg er glad i å reise, men etter at jeg fikk tilbakefallet, har jeg ikke reist noe. Jeg er ikke i form til det. Men når dette er ferdig skal jeg besøke søsteren – og ta en hurtigrutetur.	Jeg er glad i å reise og planlegger å besøke søsteren min og ta en tur med Hurtigruta når jeg er ferdig med kuren	drømme og planlegge	Å utholde lidelse ved å bevare håp
Har poliklinikken fulgt opp dine behov for hjelp hjemme? *Nei jeg har ikke blitt spurt om noe slikt på sykehuset. Men jeg må også fortelle at jeg har vært noe sløvete// De tar det vel for gitt på sykehuset at det skal gå bra..*	De tar det vel for gitt på sykehuset at jeg skal greie meg bra.		Å være oppmerksom på at man er alene
Så har jeg styra fælt for å få behandlinga tidlig neste dag slik at jeg vann først båten veit du... Og derre fikk dem da endelig inn i hodet – fra laboratoriet og opp igjennom systemet.	Jeg må selv ta ansvar for å tilpasse tidspunkt for behandlingen slik at jeg kan rekke første båten hjem. Og dette fikk de omsider forståelse for.	navigere på egen hånd	Å være oppmerksom på at man er alene
Men så hender det at jeg må vente noen timer på drosjen. Jeg får beholde sengen til kl ett. Det er nå verst. Det er trasig. Jeg vet ingen ting. Vi kan ikke bestille drosje selv lenger, og nå blir det vel enda verre. Nå er det en som skal ordne med dette, samle opp flest mulig jeg må som regel si fra meg lunsjen, fordi jeg ikke vet når jeg skal dra. Så jeg kjøper meg som regel en bolle i kiosken før jeg reiser heim	Det er det verste er å ikke vite når jeg skal dra..Vi kan ikke bestille drosje selv lenger. Nå samler de opp pasienter for å fylle drosjene	å ha lite kontroll	Å leve opp til forventninger om å være en god pasient

Hjemmesykepleien var her, men det var en ny hver gang, og så sa de det at jeg gjorde det så bra at jeg kunne gjøre det selv. For det er ikke bare å ringe etter de når jeg trenger hjelp, for det er så langt for de å kjøre	De sa at jeg klarte det fint på egen hånd. Det er ikke bare for meg å ringe hver gang jeg trenger hjelp	å unngå å være til bry	Å leve opp til forventninger om å være en god pasient
Jeg kommer meg ikke mellom hver gang. Jeg tenkte å spørre om jeg kan få ha tre uker mellom hver kur, men det har jeg ikke gjort enda// jeg er så sliten..	Jeg klarer ikke å komme meg mellom hver gang..jeg er så sliten..	å være i forfall	Å stå i fare for å miste identitet og verdi
Ja – jeg føler meg som avfall. Jeg har liksom ikke fortjent det virker det som.// men legene skulle jeg ønsket ha lyttet mer. Hørt på pasientene//..så må en ikke regne med det at alle over 70 år er aldeles senil... det finnes en eller annen som er helt grei langt oppi 90-åra. (sint)	Jeg føler meg som avfall. Det er som om jeg ikke har fortjent behandling fordi jeg er gammel	miste verdighet	Å stå i fare for å miste identitet og verdi
Før måtte jeg alltid ha noe å gjøre. Jeg har montert bunader og jobbet på aldershjemmet. Det var så enorm som jeg jobbet. Sendte bunader over hele landet. Trur jeg har montert 500 bunader.	Livet før bestod av arbeid og av å produsere	miste kontinuitet	Å stå i fare for å miste identitet og verdi

Jeg orker ikke å snakke om det hele tiden. Da blir omgangskretsen lei av meg. Når jeg ikke er så sykdomsorientert, så blir det godt å være sammen med meg. Vennene vil være sammen med meg, for jeg har så godt humør.	Jeg vil gjerne være et godt selskap for min omgangskrets. Jeg har alltid hatt så godt humør	miste kontinuitet	Å stå i fare for å miste identitet og verdi

Meanings of being old, living on one`s own and suffering from incurable cancer in rural Norway.

A qualitative study

Abstract

Purpose of the research: The aim of this study was to gain knowledge about the lived experience of elderly people, living on their own, who suffer from incurable cancer in rural Norway. How does illness and treatment influence everyday life and what meanings can be found in these experiences?

Methods and sample: Data were collected from narrative interviews with five elderly people with incurable cancer (three women and two men, aged 71 -79), receiving outpatient and life-prolonging chemotherapy and living alone in their homes in rural Norway. Phenomenological hermeneutical approach was used to interpret the meaning of the lived experience.

Key results: Four main themes were found: *enduring by keeping the hope alive, becoming aware that you are on your own, living up to expectations of being a good patient* and *being in danger of losing identity and value.* Enduring this situation means struggling with terminal illness and facing death by gritting one`s teeth, and replacing former ways of living. The process of providing treatment causes increased distress as maintaining dignity becomes more of a challenge. Being at the mercy of the systems` schedule, indebted with gratitude, it is more difficult for the elderly persons to complain or demand adjustments.

Conclusions: These results show a complex and comprehensive situation where physical symptoms and emotions are interwoven, and describes how the ways of suffering caused by the way care is delivered, suffering related to the cancer disease and existential suffering, may increase each other's impact. The social and rural context calls for special attention as the patients lack the power to force their case through. Their comfort depends to a large extent on health professionals' sensitivity.

Keywords: Incurable cancer, elderly people, rural care, suffering, dignity, phenomenological hermeneutics

INTRODUCTION

This study constitutes the second part of a larger study aiming to draw attention to the need for, and the delivery of, palliative care to elderly people living alone and suffering from life threatening disease in rural areas. A current study (Wiik et.al. submitted 2011) found that elderly people with incurable cancer experienced arduous and trying commutes to treatment. Their situation was characterized by substantial physical and emotional exhaustion. The findings indicated that these elderly people had to "walk the palliative way alone" without having necessary coping ability or accessible help. By a second analysis this study aims to find the meanings of the informants lived experience. How does illness and treatment influence everyday life and how does it impact on their social relations and attitude towards life?

Elderly people represent a majority of cancer cases in Norway. Statistics from the National Cancer Registry (2008) shows that half are diagnosed at the age of 70 or older and 40 % of all new cases occur between 50 and 69. As life expectancy increases over 1000 000 inhabitants are expected to be aged 65 or over by 2030. More than two thirds of the population in small communities in Norway will be older than 67 years within 20 years (Hjorthol, 2011)

While much is achieved in making cancer care supportive little attention has been given to cancer and the burden to understand how this is incorporated in people's lives as they age (Thomè et.al., 2003; Esbensen et.al.,2006; Blank and Bellizzi, 2008; Beck et.al., 2009; Schlairet, 2011).

Old people diagnosed with cancer face severe challenges not only due to the illness. Aging experience also entails changes that potentially leave the individual in vulnerable situations. Decline in functionality and co-morbidity is common and loss of spouses and friends along with shifting social role may influence psychological adjustment (McCaffery, 1994).

As in other European countries, outpatient treatment in Norway plays an important role when it comes to meeting demands for efficacy and quality, as well as fulfilling patients` desire to stay in their homes for as long as possible. Services taken for granted in urban areas may still be limited in rural districts (Harris et.al.2004), and access to treatment and care may involve long- distance travel for remote patients, and cause significant strain, particularly for elderly patients (Smiths and Campbell, 2004).

Although old rural patients may be more dependent on public health services, they are more likely to use informal support than those living in urban districts (Coward et al., 1990;

Montoro-Rodriguez et al., 2003; Bedard et al., 2004). As the agenda of the Norwegian Health Department (2008-2009) is to provide stronger community health care and improve coordination between services this study intends to pay attention to the rural context. Experiencing life threatening disease causes suffering regardless of age, and entering the patients` world means, according to Katie Eriksson(1997), to enter a world of suffering. Relieving agony, which is the very idea of caring, implies understanding it. Thus, it is necessary to listen to those experiencing this situation and hear what they emphasize as they reflect on their lives.

METHOD

A qualitative approach was chosen in this study because when studying people's experiences and understanding about their lives and world it seems important to talk to them, with the purpose of trying to understand the world from their point of view. An individual's lived experience can only be caught through letting them narrate stories about it. Therefore, the data from which the interpretation originates represents personal statements/stories about personal experiences, which are always to be seen as unique.

RESEARCH CONTEXT AND PARTICIPANTS

To gain knowledge of the lived experience, our sampling-strategy was based on the following criteria: people suffering from incurable cancer, aged 70 years or over, receiving outpatient treatment – life-prolonging chemotherapy and living alone in their homes in rural areas. Contact with eligible candidates was mediated through an oncologic policlinic in a local hospital in Norway. Seven candidates were considered eligible, of which five gave written consent to participate. The recruiting procedure is described in detail elsewhere (Wiik et. al., 2011 submitted).

Three women and two men participated in the study. They were aged from 71 to 79 years (mean 76.6) and the time from being diagnosed varied from 6 months to 9 years. At the time of the interview they all received palliative and life-prolonging chemotherapy in a policlinic.

They resided in rural areas (representing coastal communities and mountain communities) where travelling to the outpatient treatment and back home(including waiting for transport lift) took from 3 hours to 12 hours(mean 7,6 hours). Four of the five travelled by cab, but the two men chose private transport later on. One of the men had to catch a ferry and a woman had to go by both bus and ferry, as she lived in another county.
The women had been widowed for several years and the men were bachelors. The main assistance and help was offered from family and neighbors. Some of them had received help from the community health care for a short period. Daily network consisted of contact with a son or a daughter for two of the participants, one had a brother living next door, and one had a good neighbor. The fifth participant had no daily personal contact with the network. Except for one woman, who temporarily stayed in a neighbor's house, they lived alone in their own houses.

DATA COLLECTION

The data collection was performed through narrative interviews with broad open-ended questions (Patton, 2002). The interviewees were asked to choose and speak freely about their daily life situations and how they experience them. According to Kvaale (2007) there is a mutual dependence between human interaction and production of knowledge in an interview situation. The theme was introduced in a flexible order and adjusted to the situation so that the informants were able to express thoughts that they considered important. They were asked to narrate their stories about the following themes:

- What they think is important and gives them strength to manage their daily lives
- Their experiences of living with cancer
- Their thoughts about and experiences with chemotherapy and the journey to the treatment site and back home.

They were encouraged to narrate about specific situations and to reflect about their emotions, thoughts, and actions (Drew, 1993). Each interview lasted 55-125 min, and was tape-recorded and transcribed verbatim.

ANALYSIS OF DATA

We used a phenomenological-hermeneutic approach, inspired by the philosophy of Ricoeur (1976), to shed light on the informants' lived experience of their daily life undergoing palliative chemotherapy treatment. Ricoeur (1991) states that when there is a language of symbols and metaphors, there is also hermeneutics. Single acts must be seen in a relationship, and the relationship must be seen in light of the single act. The text comes with a meaning (utters meaning), and the reader then makes the reduction and seeks his or her meaning depending on the phenomenon that is to be illuminated (utterance meaning). The authors of this study have pre-understandings that might influence our interpretations. Two of the authors have experiences of working with cancer patients and geriatric patients. The method combines phenomenological philosophy with hermeneutic interpretation in a dialectic process (cf. Ricoeur, 1991). It was developed for use in nursing research at the Department of Advanced Nursing, Umeå University, Sweden, and the Unit of Nursing Science, University of Tromsø , Norway (Lindseth & Norberg, 2004), and has been used in several qualitative studies, such as Rasmussen, Sandman and Norberg (1997) and Skovdahl, Kihlgren and Kihlgren (2003).

In this analysis, we sought the utterance meaning, that is, what can be deduced from the text. The analytical process was performed in three steps:

1. First, a naïve reading was performed in order to formulate a preliminary interpretation of the text, and a naïve understanding of the meaning of living alone with incurable cancer was formulated as a starting point for further analysis of the text.

2. The second step comprised an analysis of a number of ''wild guesses'' that had emerged in the naive reading, in order to verify or falsify them. This second step involved a thematic analysis. In order to expose the meaning, the text was sorted on the basis of different narrations of experiences, guided by questions such as ''what situations are the informants talking about when narrating about their everyday life as a home living palliative patient?'', and thereafter condensed and thematized. The text segments that expressed meaning were then arranged in themes (Table I).

3. In the third and final step, an interpreted whole was formulated on the basis of the naïve reading, the structural analysis (including the use of metaphors and the personal pronominal), and the authors' pre-understanding.

ETHICAL CONSIDERATIONS

The regional research ethics committee of Northern-Norway approved the study (No. 4.2007.1149). The participants were informed about the purpose and procedure of the study both orally and by a letter. They were assured confidential treatment and written consent was established. If telling their story might lead to any distress they had the opportunity to talk to a psychiatrist.

RESULTS

Naïve reading

Participants describe an exhaustive life, finding themselves in a conflicting state of hope and despair. Their stories reveal feelings of being on their own having to rely on the help from neighbors or relatives. The local health services are considered not useful or unavailable when needed. Experience of being neglected and seen as a burden arises often. Some of the informants find the meeting with health professionals humiliating - it gives them a sense of being of no value. It feels unfair having to fight for the right to be examined and receiving treatment. The offer of chemotherapy treatment in spite of old age is considered very important. It holds hope for improvement and awakens a trust that doctors will do their best. It also appears to be an acceptance which restores dignity. Nevertheless keeping this dignity demands a humble attitude and they do not want to complain. Organizing treatment – travelling, ordering tests and appointments - takes energy and exposes to stress. Paradoxically, this empowerment may become a burden and even leave them with a sense of worthlessness. In addition they have to face bodily decline and a situation where end of life is near. The preoccupation with staying alive and taking every day as it comes reduces their life to a small world. Little energy is left for activities that earlier made life worth living.

STRUCTURAL ANALYSIS

The analysis is presented in four themes as follows:

- Enduring by keeping the hope alive
- Becoming aware that you are on your own
- Living up to expectations of being a good patient
- Being in danger of losing identity and value

ENDURING BY KEEPING THE HOPE ALIVE

All interviewees demonstrate a strong will and hope for survival. None of them seem to have given up, and day after day is endured with an impressive strength. Receiving chemotherapy appears to play the major role in keeping one`s spirit up. Although they seem to be aware that treatment cannot heal, it is perceived as an opportunity to delay. Treatment implies an active problem solving approach. Someone has faith and the will to help.

One of the men says:

> *The doctor said I could live another year if I took this poison..it`s like borrowing more time..// My mother got cancer in the stomach.. she got very sick...You know, there wasn't as much help in those days – she didn't get any chemotherapy. It is better today..*

One woman says:

> *Yes, it is the hope to get well that gives me the strength..at least to function fairly well*

Sub-theme: Having confidence in the expertise at the policlinic

The contact with healthcare professionals at the policlinic is highly appreciated. The informants have a common experience of being neglected and brushed aside when the first symptoms showed up. This is mainly related to the perception of general practitioners` attitudes of indifference. Finally receiving the hospital`s competence and help inspires hope and it occurs to be a relation that is deeply dependent on the staff. The care provided is looked upon with gratitude and approval.

One woman says:

> *They organize everything at the hospital..medicines and such..there I can ask questions and complain(laughs).. That's nice..// They sit down and talk when they have time... I must keep on – if I don't take it (the chemotherapy) I won't get well..*

Sub-theme: Coping with conflicting feelings

Hope and despair pervade their experiences. They try to cope by suppressing doubts and anxiety and focus on the positive sides. There is no other way to get through it but to carry on and take whatever comes. One woman describes it as living in a constant tension which leaves her in a position of feeling nor happy or sad.

> *I really don't know how I would react if someone told me that I had recovered. It sounds strange, but this is how it feels. All the time you go there and prepare for the worst..Yes, it is so stressful, and you become..(sighs) like that..I don't ask so many questions, I can't bear the negative answers, I leave that for later. Now I only want to hear positive things- it makes me stronger.*

Sub-theme: Dreaming and making plans

Enduring also implies having dreams and planning for the future. They still engage in life, and by living as normally as possible, illusions of better days ahead are created. These illusions are grasped as opportunities and become important parts of the hope.

One man who has been fishing all his life says:

> *I have sold my boat, but I wish someone could take me out fishing again..It would be fun to sneak off..*

One woman plans her travelling:

> *I love to travel, but lately my condition has not been good. I intend to visit my sister and maybe go for a voyage after finishing this treatment.*

Theme: Becoming aware that you are on your own

The narratives reveal a lot about how the elderly people are assumed to care for themselves. Though they are familiar with living and managing alone, their independence is potentially threatened by the illness. In some cases maintaining autonomy encourages coping through mobilizing of personal resources.

One man describes this ability with much pride:

> *I have been alone all my life so I'm used to taking care of myself. I travel alone to treatment of course – I'm not yet that poorly.*

All informants find it difficult to ask for assistance, and the fear of causing someone inconveniences is strongly present. Even when their situation may be overwhelming, they seem reluctant to ask for help. One has temporarily moved to a neighbors` house and she is comfortable with the situation because she didn't ask for it:

> *I presume he is fine with the arrangement. It was him that offered me to stay in his house for the winter..*

Practical help is received when necessary from their family but the informants tend to bother as less as possible. The most important contact with the family occurs to be on the emotional level. One woman describes this meaning:

> *The most valuable is that my family still loves me. They send cards, call me on the telephone and come round if they are at home. They care. They ask me how I am.*

Another woman says:

> *When I come home from the hospital my daughter has lit the fire. But I try not to bother her if it's not necessary.*

When asked whether the policlinic has followed up or guided their homecare they deny this or they can't remember.

> *No they haven't asked me about that. But I have to say that I have been a bit lax..I guess, they take it for granted at the hospital, that we will manage.*

Sub-theme: Navigating alone

Navigating through the healthcare system takes much energy and effort. They have to order tests and appointments and this often takes hours to accomplish:

> *I have to order blood tests myself, it takes time when I call and only meet an answering machine..I feel that I don't have time for this..*

Another man describes planning the commute to the hospital:

> *I had to go through a lot of trouble to get treatment early in the day so I can travel with the first ferry back home..finally they realized it from the lab and up through the system..*

Theme: Living up to expectations of being a good patient

Being a patient implies adjustment and entering a culture with certain expectations. A traditional power dynamic between patients and care-providers is confirmed by the interviewees. Their thoughts reflect their obligations of being grateful and their feelings of being at the system's mercy.

Subtheme: Having limited control

Lack of knowledge concerning symptoms and progression of the disease is a common experience. They seem to know little about effects of the chemotherapy and they don't recall much information about how to deal with it. Neither do they know how long treatment will last or if it works. They wait and ask few questions. Additionally they have limited control over practical arrangements which often leads to long waits for a bed, a meal or to have a cab home.

One woman talks about waiting and not knowing:

> *Sometimes I wait hours for the cab. I can keep the bed until one o'clock. That's the worst. Not knowing. We aren't allowed to order a cab by our self anymore..there is a person taking care of it - gathering patients to fill up the cab...// Usually I must call off the lunch because I don't know when I am to leave. So I buy a bun in the kiosk before I go home.*

Subtheme: Avoiding becoming a burden

Being a good patient also takes a humble and compliant behavior. Some of the informants struggle with figuring out how to please the system: One woman states:

> *You can't easily reach a doctor up here. And if we call too often – it feels like we inconvenience them, and when we come to appointments they ask why we didn't come before..no it is not easy..*

Community health care appears to be distant and not so available. The system offers little help and the informants have few demands. Two of the women feel they cause inconvenience and feel guilty about receiving homecare (help with a wound and a stomy).

> *Every time a new person would come, and they told me I did fine on my own. They have a long way to drive and I was told that I couldn't just call every time I needed help.*

Theme: Being in danger of losing identity and value

The narratives expose a shrinking life world where dealing with alterations and loss occupies most of the energy. Feelings of being on the decline are highly present and influence their self-esteem and quality of life.

Subtheme: Being in decline

All informants have physical symptoms complicating daily living. Their nutritional situation is poor and weight loss is tangible. Bodily changes become visible signs and emphasize their decline.

A woman says:

> *I used to weigh 80 kilos, now I`m 64..My clothes don`t fit me anymore..//You see, I have something on my tongue.., they (at the hospital) said it was fungus..and I don`t have any appetite..the food doesn`t taste anything..it`s a different taste..*

Tiredness is described as the most troublesome symptom. One woman states:

> *I am not able to recover between the cures. I have planned to request a three weeks break between the treatments, but I haven't done it yet..//I feel so tired..*

Subtheme: Losing dignity

The contact with some health professionals gives rise to feelings of inferiority. They are met with refusal and feel they are exposed to ageism. It awakes anger and sadness. One man says bitterly:

> *Yes, I feel like rubbish..It`s like I haven't deserved it (the treatment)// I think the doctors ought to listen more to the patients..you can't judge everybody past the seventies to be senile..//I think it`s odd that they won`t treat older people (angry)*

A woman says:

> *The general practitioner thinks that if it is cancer..then you have it everywhere....and there`s nothing to do about it..//She said she would send in the urinary-sample..but she never did..// I got a fourth cure of antibiotics treatment..but it didn`t help..*

One of the men refuses to take the cab when it is filled up:

> *I don't like talking to strangers..people around here are so nosy. I won't let them se me this sick..*

"Not owning your own case" is another aspect of devaluation. Feelings of being treated with no respect arise when others become the "experts". One of the women says:

> *When I visit people, they start talking about cancer, that's the worst.. then they know everything....this and that..what it`s like..*

Subtheme: Losing continuity

The narratives reveal mourning for their past life. The loss of energy accompanying illness and therapy prevent them from keeping up former activities. Additionally, age itself brings functional limitations and necessitates a change in lifestyle. It seems important to highlight the person one used to be and give credit to achievements from earlier days. One of the women says:

> *I used to work a lot in a nursing home and I must have assembled at least 500 national costumes.*

Another man talks about a life of hard work and responsibility:

> *I grew up on an island before the war, ..at the age of 14 I was treated as an adult..// I have worked hard all my life, and now I benefit from that..I was in good physical shape..*

When telling their stories the informants begin to reflect on their relation to others.

One of the women asserts the importance of maintaining her social network and her identity in relation to her friends:

> *I can't talk about the cancer all the time. My acquaintances would become fed up with me. When I am not so disease-oriented, then I am fun to be with. My friends want to be with me because I am always so cheerful.*

Comprehensive understanding

Our interpretation suggests that, for the old and home living palliative patient, quality of life as well as life itself is at risk. Enduring this situation means struggling with terminal illness and facing death by gritting one`s teeth, and and replacing former ways of living. The process of providing treatment causes increased distress because maintaining dignity becomes more difficult. This is seen as a paradoxical effect as the health care system "empowers" the patient to a position of less control and cooperation. Being at the mercy of the systems schedule, indebted with gratitude, they feel they`re not entitled to complain or demand adjustments. There seems to be a disparity between patients` needs and the help that is offered, or perhaps - *how* it is offered.

DISCUSSION

The aim of this study was to explore and understand the lived experience of elderly people living alone and suffering from incurable cancer in rural Norway. We found four themes, some of them with subthemes, shedding light on their experiences; *Enduring by keeping the hope alive, becoming aware that you are on your own, living up to expectations of being a good patient and being in danger of losing identity and value.*

The will to live and hold on to life is strongly present in the narratives, and hope appears to be a key to endure the distress.

The most important source to hope exists in having the chemotherapy. Having treatment means that someone cares and represent a grasp at straws. Letting the hope guide the endurance seem to be a choice because there is no other way through. This robust coping ability is somehow surprising as one may think that old age would lead to a more passive and

hopeless attitude. Death is no longer remote or abstract as people get older. Earlier research has also showed that younger cancer patients, at terminal stages, experience more hopelessness than elderly patients (Mystakidou et. al., 2009). Age is however only one predictor related to hopelessness. Grief and depression are other significant factors influencing presence of hope or hopelessness (Mystakidou et. al., 2009). The way someone reacts to illness also depends on their cultural context; where they live, they way they relate to other individuals, and the attributes he or she associates to life and death (Mystakidou et.al. , 2004 -2005).

Hope is present in this material as something tangible – the hope to stay alive. This hope is not understood as death- renouncing but rather life-affirming, also shown by Eliott and Olver (2009). Hope can be looked upon as a power in the coping process elucidated in their handling of conflicting feelings and in the way they dream and make plans for the future. This is similar with findings in other studies where elderly patients with advanced illness define hope as an inner resource and a coping mechanism (Duggleby and Wright, 2005; Elliott and Olver 2009).

The theme enduring by keeping the hope alive may indicate an urge to be confirmed and recognized as an equal human being, and it defies prejudices saying that life in old age has nothing more to offer. In this meaning hope contrasts or neutralizes the negative power which is found in the latter themes showing the devaluation and care that diminishes the patients' dignity.

Along with hope and the will to keep on living, suffering caused by the way care is delivered (or not delivered) stands out as the most striking content in the narratives.

Viewed from the patients' perspective meetings with health care providers occurs to be a potential threat to well-being and dignity. Understanding this lived experience means entering the patient's world – a world of suffering (Eriksson 1997). According to Katie Eriksson (1995) there are three ways of suffering (suffering caused by illness, suffering caused by care and suffering related to the life situation) affecting meanings of being a patient.

Eriksson (1995) divides the *suffering caused by care* into four categories; insulting the dignity of the patient, condemnation or punishment, misuse of power and absence of care.

Our interpretation of the lived experience indicates considerable threats to dignity. The informants feel they are victims of discriminating attitudes. Having chemotherapy at their age is not something to be taken for granted. It is looked upon as a blessing and a charity. Younger cancer patients are more likely to be treated with chemotherapy than elderly

(Ayanian et. al., 2003). Because of perceived minimal benefit and risk of toxicity, physicians tend to under treat elderly patients (Dale, 2003). Our informants seem to pay more attention to the injustice than to the biological basis. They find the initial rejection humiliating and not understandable. They end up with anger and disappointment. It makes them feel lesser as people and some identify themselves as garbage. In this position of shame it is not easy to ask for more. All narratives are colored by this theme and it comes out in various reactions from anger to bitterness and acceptance. A Canadian study (Cochinov et. al., 2006) found similar results showing that 87, 5% of palliative care patients felt they were not treated with respect or understanding and felt they were a burden to others. This was the most significant issue affecting their dignity.

The fear of causing other people inconvenience is strongly present in our analysis. These concerns are addressed to both formal and informal helpers, and gives rise to an awareness of being on their own. In contact with their family and social network they wish to make a good impression and be a pleasant company. Like other findings (Thome` et. al., 2003), thoughts about this relationship are concerned with feeling closeness and they worry about being regarded as troublesome. They sense that giving the disease too much attention can affect social interaction and their own self-esteem. This was also found by Kralik et.al.(2004)) as a behavior to avoid placing strain on others and protect the self. In most cases the family members reside far from the informants and the most appreciated care is having their love and thoughtfulness. Turning to relatives or friends is considered to be a last resort. In this sense, awareness of being alone can provoke anxiety and underline feelings of being abandoned.

On the other hand, realizing that you are alone may as well catalyze coping ability. Our informants show an impressive mobilization of personal strength and will to carry out self-care. In this instance age and life experience may be regarded as an advantage, because the informants are familiar with living alone and make use of resources built up through a life time.

Living up to expectations of being a good patient increases patients` effort to be independent and less troublesome. Pleasing the system and trying to fulfill what they think is expected can also serve as a means to maintain dignity.

Dignity as a concept can be explained to be connected to the "human office" dealing with equality and trustworthiness (Eriksson, 1995). From this follows that dignity is an absolute value demonstrated through the ability to be responsible and independent. In one way the

elderly persons are left to control and arrange for themselves (ordering tests, appointments etc.). Although, they seem to be empowered patients, this may be only illusory. The conditions of the system are looked upon as vague and unverifiable. One example is the hospital`s handling of the transport. The patients are not trusted to organize transport by themselves, and having to sit in a cab filled up with strangers feels awful. Another issue is the long periods of waiting and not knowing what will happen next. Furthermore they do not have sufficient information about the progression of the disease or the treatment and how to deal with side-effects. Lack of knowledge about how to handle symptoms and to understand the implications of physical complications is also found in other studies (Melin-Johansson et. al., 2008; Sægrov and Haldin, 2004). Health professionals` guidance or consultation about choices and future perspectives is hardly mentioned by our informants. Their statements indicate an implied acceptance of the situation as they are told that they manage just fine on their own. And it is pointed out to them that services are not available each time because they reside off the beaten track. Even if there are acceptable reasons complicating an optimal care scenario, such messages can silence the patients and lead to relinquishing of rights. Research gives reason to believe that cancer patients in general, and particularly those who are socially disadvantaged, have considerable unmet needs for information and help with navigating for care (Carroll et.al., 2010). The referenced study showed that having a trained lay-person helping the patient to facilitate care throughout the treatment period was valued as a bridge between a fragmented, poorly coordinated health-care system and the complex needs of the patients.

The last theme; being in danger of losing identity and value represents a further dimension of their suffering and can be discussed in the light of suffering caused by the illness and suffering life itself(Eriksson, 1995).

Suffering caused by the illness refers to experiencing bodily decline. Fatigue is the most pronounced symptom. The informants appear worn out and they are not able to recover between the treatments. Despite problems with coping, for example problems with weight loss and eating, they do not call for attention or help. This result is concurrent with other studies (Hagelin et.al., 2009 and Kenefick et.al., 2006) finding that patients living with their partners report significantly more symptom distress than those living alone. When sharing household, symptoms become more obvious to others and therefore more legitimate to express? Fatigue is demonstrated to have negative influence on quality of life (Benzein and Bergh, 2005; Hagelin et.al., 2009) and is described as a subjective experience of physical or

mental exhaustion (Ryan et.al., 2007). Moreover, fatigue is seen as one of many threats to hope (Miller, 2007).

According to Eriksson (1995) physical deterioration may as well give rise to feelings of guilt and shame, and these narratives shows examples of attempts to hide one`s misery. The elderly persons state their dislike of being watched and judged by other people. This may not only be a matter of escaping other peoples nosiness, it can also lead to neglecting needs for help.

People stricken by chronic illness find that certain life stories are interrupted, the sense of coherence is undermined and the future becomes uncertain and unpredictable (Corbin and Strauss, 1987). Some theorists assert that one's identity is established in early adulthood and remains stable throughout life (Erikson, 1989), while others suggest that identity might undergo a crisis and transform as frailty challenges adjustment in old age (Fillit and Butler, 2009). The literature shows agreement in two defining components of personal identity; continuity in "one`s" sense of identity and awareness of being different from others (Gillies and Johnson, 2004). The informants in this study are highly affected by the strain and frailty experienced in both aging and illness. They are prevented from continuing familiar ways of living and have to re-organize activities to make goals achievable. In many ways this process involves putting life "on hold"- whilst waiting to see if opportunities can be revived. Some statements in the interviews give rise to doubts whether the informants actually understand how sick they are. Their statements come out in contradictory meanings; on the one hand dreaming and planning as if they will recover the next day, and on the other showing acceptance that death is soon ahead. A possible interpretation is that surviving this conflict of feelings mirrors the psychological capacity of individuals to transform reality (Baltes and Smith, 2003). Earlier studies have shed light on the remarkable ability people have to regulate the subjective impact of health-related losses (Baltes and Smith 2003). This reaction also fits Eriksson`s theory (1995) saying that the threat of destruction (also in non-literal meaning –as not being recognized) interferes with the will to live and fight. What is obvious is the strong need for displaying their personality, acknowledging the person one used to be, and showing that this person is still here.

In order to provide good palliative care it is necessary to explore and understand the distress and risk factors that influence the lived experience of cancer patients. Many sources of distress may not be readily visible or easily articulated by patients (Chochinov, 2009). The

present study confirms this impression which stresses the importance of making their voices heard.

Research on how cancer affects patient's lives is mainly occupied with the managing of physical symptoms (Boström et.al. , 2004; Grössman et.al.,2006). Enduring the illness, though often involves considerable psychological, social and spiritual suffering along with deteriorating physical health (Fegg et.al. , 2010). A Norwegian study (Sægrov and Halding, 2004) found that cancer patients missed some program available to care for their psycho-social needs, and felt they were left to their own resources during a period of being physically and mentally drained. The narratives in this study exemplify this complex and comprehensive situation where physical symptoms and emotions are interwoven and how the three ways of suffering interfere and may increase each other's impact. We found the impact of physical symptoms being overshadowed by the suffering due to loneliness, feelings of worthlessness, and fear of becoming a burden. The need to be confirmed, appreciated and treated with respect imbued in this lived experience and reconciliation to life and own integrity, seems more important than accepting end of life.
The analysis revealed unmet needs that are poorly flagged. The informants may have varying awareness of the needs, or difficulties in expressing them, and it may even be hard to see what help there is to ask for. The results of the study highlight areas of crucial importance to the affected elderly patients in maintaining credible sense of self, and those charged with providing treatment and care should make attempts to learn from these individuals in this process. What these cancer patients have shed light on through their stories may not differ in general from other patients suffering from life threatening illness, but their social and rural context calls for a special attention because they lack the power to force their case through. The patients` comfort depends to a large extent upon health professionals' sensitivity.

METHODOLOGICAL CONSIDERATIONS

The findings through this research method must be seen as a unique synthesis of what the text has taught us, of what theoretical stand we take and how we have integrated all this within our personal experience. It is also important to notice that interpretations of the findings are based on the unique experience of those who shared their stories. The intention is not to generalize

the findings but to contribute to a process of revision and enrichment of understanding. The theme *enduring by keeping the hope alive* is quite surprising compared to results from other studies. Benzein and Bergh (2005) and Hagelin et.al.(2009) found that patients with terminal illness who are struggling with fatigue, report hopelessness and poor coping ability. How can our informants express hope in this hopeless situation? A possible explanation could be rooted in their manner of communicating or their cultural context. Living alone might also lead to the presumption that our informants are not accustomed to, or have few opportunities to plainly express thoughts about life and death. Existential issues are usually broached with close relations and might be difficult to speak openly about to a stranger. Besides, expressing hopelessness could potentially increase their vulnerability and confirm the misery when they already feel valueless. The construct of hope is multidimensional (Miller, 2007) and our material is not allowing further conclusions. Our main focus was however the subjective experience of the respondents.

The present study had a small number of informants and they were recruited from communities with few inhabitants. A larger sample might have brought to light more differences and shades.

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Tab.1: Examples of meaning units, condensed meaning units, sub-themes (when present), and themes

Meaning units from the text	Condensed meaning units	Sub- theme	Theme
The doctor said I could live another year if I took this poison..it's like borrowing more time..// My mother got cancer in the stomach..she got very sick..You know, there wasn't as much help in those days – she didn't get any chemotherapy. It is better today..	The doctor said I could live another year, and have borrowed time if I took this poison. Treatment today is good.		Enduring by keeping the hope alive
They organize everything at the hospital..medicines and such..there I can ask questions and complain(laughs).. That's nice..// They sit down and talk when they have time... I must keep on – if I don't take it(the chemotherapy) I won't get well..	They organize everything at the hospital. They have competence and medicines. They take care of me.	having confidence in the competence at the policlinic	Enduring by keeping the hope alive
I really don't know how I would react if someone told me that I had recovered. It sounds strange, but this is how it feels. All the time you go there and prepare for the worst..Yes, it is so stressful, and you become..(sighs) like that..I don't ask so many questions, I can't bear the negative answers, I leave that for later. Now I only want to hear positive things- it makes me stronger.	It is so stressful..I go there and prepare for the worst..I avoid asking too many questions – I only want to hear positive things. It makes me stronger	coping with conflicting feelings	Enduring by keeping the hope alive
I love to travel, but lately my condition has not been good. I intend to visit my sister and maybe go for a voyage after finishing this treatment	I love to travel and I intend to visit my sister and go for a holiday after finishing the treatment	dreaming and making plans	Enduring by keeping the hope alive

Have the policlinic followed up your homecare or questioned if you need any help in your home? *No they haven't asked me about that. But I have to say that I have been a bit lax..I guess, they take it for granted at the hospital that we will manage..*	I guess they take it for granted that we will manage on our own		Becoming aware that you are on your own
I had to go through a lot of trouble to get treatment early in the day so I can travel with the first ferry back home....finally they realized it from the lab and up through the system..	I have to coordinate time for treatment to make sure that I can correspond with the first ferry back home	navigating alone	Becoming aware that you are on your own
Sometimes I wait hours for the cab. I can keep the bed until one o'clock. That's the worst. Not knowing. We aren't allowed to order a cab by our self anymore..there is a person taking care of it - gathering patients to fill up the cab...// Usually I must call off the lunch because I don't know when I am to leave. So I buy a bun in the kiosk before I go home.	That's the worst part- not knowing when to leave..We aren't allowed to order a cab by our self anymore..They gather patients to fill up the cabs	having limited control	Living up to expectations of being a good patient
Every time a new person would come, and they told me I did fine on my own. They have a long way to drive and I was told that I couldn't just call every time I needed help..	They said I did fine on my own. I was told that I couldn't just call every time I needed help..	avoid becoming a burden	Living up to expectations of being a good patient

I`m not able to recover between the cures. I have planned to request for a three weeks break between the treatments, but I haven't done it yet..//I feel so tired..	There is no time to recover. I feel so tired	being in decline	Being in danger of losing identity and value
Yes, I feel like rubbish..It`s like I haven't disserved it(the treatment)// I think the doctors ought to listen more to the patients..you can't judge everybody past the seventies to be senile..//I think it`s odd that they won`t treat older people (angry)	I feel like rubbish..It`s like I don`t deserve treatment because of my old age	losing dignity	Being in danger of losing identity and value
I used to work a lot in a nursing home and I must have assembled at least 500 national costumes	Life before consisted of working and producing	losing continuity	Being in danger of losing identity and value
I can't talk about the cancer all the time. My acquaintances would become fed up with me. When I am not so disease-oriented, then I am fun to be with. My friends want to be with me because I am always so cheerful	I want to be pleasant company for my friends and stay cheerful as I used to be.	losing continuity	Being in danger of losing identity and value