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BERÄTTELSER OM ENSAMHETENS VARDAG HOS MÄNNISKOR MED PSYKISKA FUNKTIONSHINDER

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ABSTRACT

This dissertation deals with people with mental illness that currently live in their own accommodation in the community. Common to all mentally ill people is their serious difficulties in carrying out activities and meeting needs in important areas of life. Terms such as "normalisation" and "integration" into the community of this group were important words full of promise at the time the psychiatric reform was carried out. However, there is some strong evidence that the psychiatric reform has not been completely successful. Despite the knowledge that loneliness and social isolation commonly occur among people with mental illness, there is little research that describes how mentally ill people themselves experience their life situation.

The overall aim of the dissertation was to gain deeper understanding of the life situation of people with mental illness via their own narratives on how their day-to-day life appears to them, and through this gain knowledge of the type of support needed for them to live a satisfactory life.

Various data acquisition methods were applied. **Study I** involved in-depth interview of two men and two women on their daily life. Data acquisition in **Study II** was via participant observations at an activity unit for people with mental illness. Photographs were used for **Studies III** and **IV.** Eight informants were issued with disposable cameras and asked to take approximately 10 pictures of objects, situations and/or individuals. These photographs were then used as a basis for follow-up interviews. Results from **Study I** showed that informants were aware both of their illness and their psychosocial disadvantages, and that they had insight into what was required of them to influence their situation, while simultaneously having insight into their poor ability to take initiatives. Informants in **Study II** experienced themselves as unwelcome, vulnerable and marginalized individuals with little hope of a change in existence, resulting in anxiety over the future. They felt trust was lacking in relation to other people and experienced themselves as not accepted in the company of others or by society. **Study III** provided description of informants occupied with themselves and their existence. The informants tell of a form of spirituality giving them a sense of peace and tranquillity, but which only exists for them at the beginning and end of life.

Animals are more loyal than people and make no demands, but are however, according to the informants, in a position of dependence on humans. Possessions are of significance to the informants, meaning they see their possessions as part of themselves.

In **Study IV** informants related how they would like their future to appear. They also told what having an identity meant to them, how identity is formed in individuals, what having a mental illness and feeling good means. The informants showed a longing to be seen, but at the same time not wanting to be seen. Finding a meaning with life was important since it could end at any moment.

In summary, the findings point to an existential loneliness that consists of a life pattern consisting of an interaction between the impact of the mental illness and the identity as a mentally ill person, feelings of marginalized and abandonment. Experiencing that life has a meaning, possibility of social exchange and a sense of control seem to be important for the persons with mental illness in this study.

Consequently, it can be inferred that if the care of people with mental illness pays attention to the dimensions of existential loneliness persons with mental illness may be helped to experience that life has a meaning despite their disability.

Keywords: ethnography, existential loneliness, photography, participant observation, mental illness

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INTRODUKTION

Min yrkeserfarenhet av att vårda och att ge stöd till personer med psykiska funktionshinder, inom socialtjänst såväl som psykiatrisk vård, har givit mig många insikter. En av dem är att personer med psykiska funktionshinder ofta lever ett ensamt liv som präglas av ett socialt utanförskap när de skrivs ut från institutionsvård till eget boende. Kontakterna som de har är med vårdpersonal inom öppen psykiatrisk vård och personal inom socialtjänstens boendestöd och dagverksamhet. Det sociala nätverket med nära vänner, föräldrar och syskon är begränsat. Arbetsuppgifterna inom dagverksamheten består av enklare, oavlönade sysslor såsom trädgårdsarbete och hushållsarbete. Avsaknaden av lön innebär att de ständigt har ekonomiska bekymmer eftersom den tidsbegränsade sjukersättningen oftast ligger på existensminimum.

Min grundsyn är att människor med psykisk sjukdom har samma rätt att leva ett fullvärdigt liv som alla människor har. Min uppfattning är också att de ska vara delaktiga i processen som leder till detta. I mitt yrke som sjuksköterska har jag dessvärre upplevt att personer med långvariga psykiska funktionshinder ofta är passiva och initiativlösa. Som en konsekvens av detta ”tar personalen över” varför planeringen för patientens vård vanligtvis är baserad på personalens uppfattning om vilka aktiviteter som bör ingå i patientens dagliga liv.

Att känna att livet har en mening är grundläggande för människans existens, det är även en drivkraft och en hjälp att klara av svåra och komplicerade livssituationer som uppstår på grund av sjukdom. I vårdandet vägleds sjuksköterskans av en vårdvetenskaplig människosyn som innefattar att människan ses som en meningssökande varelse. I mötet med en människa som har en svår eller komplicerad livssituation på grund av sjukdom kan hennes behov enbart förstås utifrån en helhetssyn där människan står i centrum. Så långt som möjligt utgår vårdandet från patientens livsvärld och dennes sätt att uppleva, förstå och beskriva sin vardagsvärld. Följaktligen vägleder den vårdvetenskapliga människosynen vårdforskningens kunskapsintresse, metodologi samt etiska överväganden.

Det initiala och övergripande syftet med avhandlingen var att få en djupare förståelse för det dagliga livet hos personer med psykiska funktionshinder. När jag reflekterade över resultaten i den första delstudien blev det för mig tydligt att det dagliga livet hos informanterna som ingick i studien kännetecknades av social ensamhet. Kärnan i denna ensamhet tolkade jag som ett existentiellt tomrum vilket är fokus för de efterföljande delarbetena.

BAKGRUND

Psykossjukdom och utanförskap

Historiskt sett har det funnits olika förklaringsmodeller till psykisk sjukdom men oavsett vilken teori som råder har människor med psykiska sjukdomar alltid drabbats av ett socialt utanförskap och betraktats som otillräckliga och oförutsägbara som samhällsmedborgare. Människor med psykisk sjukdom isolerades från resten av samhället. De fick ofta lida fysiskt och psykiskt med plågsamma och bestraffande behandlingar utan någon insyn eller förståelse för deras utsatthet (Svedberg, 2002). Efter det andra världskriget har i stora delar av världen den samhällskritiska debatten synliggjort psykisk sjukdom genom att argumentera för en förändring av den omänskliga tillvaron för dessa personer (Svensson 1 977:1).

I Sverige byggdes sinnessjukhusen, under 1800-talet och fram till 1960-talet, för att skydda samhället från psykiskt avvikande personer och för att kunna förvara dem i en lugn och ordnad miljö (Gustavsson och Häggberg, 1993). Under 1900-talet ökade antalet vårdplatser konstant fram till 1950-talet då ett antal utredningar tillsattes om vårdkvalitet. Patienternas vård skulle förbättras genom att vård och behandling skulle tillgodose grundläggande mänskliga fysiska behov, dock inom mentalsjukhusets ram. Kritiken mot vård och behandling av personer med psykisk sjukdom ökade under 1960-talet. Patienterna blev inte bättre av institutionsvård vars underförstådda uppgift var att skydda samhället genom att utöva makt och social kontroll. Istället blev dessa personer ”hospitaliserade”, ett begrepp som uttrycker hur människor som vistas länge på institution blir osjälvständiga och beroende av rutiner och (Sjöström, 2000).

I klassikern ”Asylums” som publicerades 1961 skildrar Erwing Goffman det sociala livet i mentalsjukhusets värld ur de intagnas synvinkel. Dessa mentalsjukhus eller totala institutioner bröt genom rutiner och normer ned gränserna mellan fritid, arbete och sömn.

Samtliga intagna hanterades som en grupp och den sociala kontrollen var påtagligt stark. De intagnas kontakter med yttervärlden var nästan obefintliga från den dag de spärrades in tills livets slut (Goffman, 1973).

I västvärlden, förutom Norden, började den psykiatriska vården förändrades redan under 1950-talet samtidigt som nedläggningen av de stora mentalsjukhusen påbörjades. Storbritannien beslutade 1954 om nedläggning av mentalsjukhusen, USA påbörjade förändringen under 1960-talet, Italien beslutade om en total nedläggning 1978 och Sverige 1995 (Propositionen, 1993/94: 218; Lamb och Bachrach, 20001; Quirck och Lellilott, 2001; Markström, 2003). I Italien beslutades genom en lag att en total nedläggning av samtliga mentalsjukhus skulle ske och ersättas med öppenvård, den s.k. Triestemodellen (Basaglia, 1971). I Stockholm inspirerades en psykiatrisk verksamhet av Triestemodellen och startade därför 1986, en enhet med socialpsykiatrisk inriktning (Costa, 1993; Hydén, 1993).

Szasz (1960) förespråkade en radikal argumentationslinje som gick ut på att psykisk sjukdom var ett *ologiskt problem.* Han menade att patienten inte var hjälpt av diagnosen och att användandet av diagnosbegreppet suddade ut kriterier för vad som är sjukt och vad som är friskt. Szasz menade att det som beskrevs som psykisk sjukdom egentligen var ett livsproblem som skapades utifrån relationen till omvärlden medan en sjukdom var ”organisk”. Psykisk sjukdom var ett sätt att imitera den medicinska vetenskapens beskrivning av somatisk sjukdom.

En annan kritik som framfördes av psykiatrikern Foucault (1961:1973) i boken ”The History of Madness” var att psykisk sjukdom var en täckmantel för samhällets behov av *social kontroll* och ordning. Varje samhälle har ett behov av en stigmatiserad grupp och de psykiskt sjuka fick överta den rollen från de leprasjuka som var en stigmatiserad grupp fram till 1600-talet. Synen på psykisk sjukdom legitimerades av staten som låste in avvikarna vilket alltså blev den psykiatriska organisationens uppgift. Psykiatrin växte således fram som en vetenskaplig disciplin som behövdes för att ta hand om de psykiskt sjuka så att den sociala kontrollen och ordningen i samhället kunde upprätthållas.

En för den medicinska vetenskapens kontroversiella syn på psykisk sjukdom framfördes av Scheff (1998), som menade att psykisk sjukdom handlar om att bli försatt i en *social roll.* Psykiatrin kunde omöjligen tillgodose omvärlden med en vetenskaplig och ”sann” bild av vad psykisk sjukdom var (Scheff, 1970). En människa med psykisk sjukdom bryter mot oskrivna normer som är knutna till vad som är acceptabelt eller önskvärt i en given kultur. Scheff (1970) myntade ”stämplingsteorin” som innebär att när en människa betraktas vara en avvikare eller vara psykiskt sjuk så förhåller sig omvärlden mot denne på ett speciellt sätt. Människan blir på så sätt *stigmatiserad* vilket kan ge vidare konsekvenser i dennes sociala liv.

Stämplingsteorin vidareutvecklades av Thoits (1985) genom den så kallade ”självstämplingsteorin”. Han menar att det inte enbart är omvärldens attityder som leder till stämpling utan det är individen själv som tar rollen som stämplad. Det kan tänkas att självstämpling är en process, som pågår under en tid och att det handlar om en individs uppfattning om sig själv och omvärldens uppfattning om individen. En självstämplingsprocess kommer förmodligen inte igång om individen är säker på sig själv och har andra individer att kommunicera med.

Den som har en psykisk sjukdom betraktas av omvärlden som annorlunda, vilket Derek Phillips (1963) redan på 1960-talet försökte styrka genom att undersöka vilka attityder lekmän hade till människor med psykisk sjukdom. Det visade sig att människor tog avstånd från personer med psykisk sjukdom och att det framförallt var förbundet med att de hade en psykiatrisk diagnos och var under psykiatrisk behandling.

Många år har gått sedan Phillips undersökning. En fråga är huruvida dessa stereotypa föreställningar lever kvar. I en jämförande undersökning av år 1950 och år 2000, Phelan *et al.,* (2000) framkom att allmänheten i högre grad år 2000 än år 1950 hade föreställningar om att psykiskt sjuka människor var farliga och skräckinjagande. Detta gällde framförallt psykiskt sjuka människor med diagnosen psykos. Dessa studier är genomförda i USA. Kan det tänkas att dessa föreställningar förekommer i Sverige? I en undersökning genomförd av Palmblad (1992) undersöktes allmänhetens attityder till psykisk sjukdom i samband med utflyttning av ett behandlingshem och en psykiatrisk mottagning till närsamhället. I undersökningen framkom att de boende i närsamhället hade föreställningar om att de psykiskt sjuka människorna som vårdades vid dessa enheter var farliga och opålitliga.

Ovanstående syn visar på ett objektivt sätt att se på personer med psykisk sjukdom och olika, ibland radikala förklaringar till uppkomsten av psykisk sjukdom och behandling. Det som saknas är ett individperspektiv, d.v.s. forskning om patientens egna utsagor och tankar kring sin psykiska sjukdom. Ett undantag är en studie av Rose *et al.*, (2004) som använt fokusgrupper med familjer, patienter och psykiatrisk personal som metod för att undersöka vilka barriärer det är kring familjen och den psykiatriska vården.

Psykiskt funktionshinder och psykiatrireformen

”Psykiskt funktionshinder” är en vedertagen definition av personer som till följd av psykisk sjukdom enligt den svenska Nationella psykiatrisamordningen, ”har väsentliga svårigheter att utföra aktiviteter på viktiga livsområden och att dessa begränsningar har funnits eller kan antas, komma att bestå under en längre tid” (SoU 2006: 5). Definitionen tillämpas av socialtjänsten, arbetsförmedlingen och statliga utredningar i syfte att avgränsa en målgrupp i samhället för att kunna tillgodose insatser, utvärdera effekter och kvalité samt registrera och inneha aktuell statistik.

Enligt Socialstyrelsen (SoS 1999: 1) är det känt att ca 43 000 personer boende i Sverige har bedömts lida av ett psykiskt funktionshinder.

Denna siffra kan ifrågasättas då det är sannolikt att det finns personer som drabbas av psykossjukdom men aldrig söker eller erhåller någon professionell hjälp och därför inte hamnar i Socialstyrelsens register. Andra förklaringar till att siffran kan vara låg är begreppet psykiskt funktionshinder är ett heterogent begrepp och att målgruppen för psykiatrireformen endast omfattar personer i åldrarna 18-65 år (SPF, 1996; SoS 1999: 1).

Flertalet (71 %) personer med psykiska funktionshinder har en psykossjukdom eller diagnosen schizofreni (SoS, 1 999:1). De schizofrena syndromen utgör en i praktiken dåligt avgränsad grupp som karaktäriseras av graden av bisarra vanföreställningar, hallucinationer och beteendestörningar. De förutsätts ha ett långvarigt förlopp som i förlängningen bidrar till utvecklandet av psykiska funktionshinder (Cullberg, 2000, s 153). Enligt Ottosson (2004) innebär de negativa symtomen ett funktionsbortfall som kan röra flera psykiska funktioner såsom brist på intresse, passivitet, avflackade affekter, tillbakadragenhet samt kognitiva funktionsstörningar.

Enligt Svenska psykiatriska föreningen (SPF, 1996) insjuknar ca 15-20 personer, i en befolkning på 100 000, årligen i en psykossjukdom. Prognosen för återhämtning är god för 1/3, mindre god 1/2 och dålig för 1/5. Harding (1988) har sammanställt flera undersökningar om återhämtning. Sammanställningen visar att hälften och två tredjedelar av personerna med schizofreni återvinner sin hälsa, för övriga personer har en psykisk sjukdom resulterat i ett handikapp som hindrar dem från att fungera i det dagliga livet utan kontinuerligt professionellt stöd.

Genom förändrat fokus - från kronisk sjukdom till handikapp - förändrades också språkbruket från kronisk psykiatrisk sjukdom till psykiskt funktionshinder, från vård till omsorg, från institutionsvård till eget boende och från patient till brukare (Eisenberg, 1977; Socialstyrelsen 1 999:1). Psykiatrireformens intentioner var att skapa goda förutsättningar för att personer med en psykisk sjukdom, som kräver långvarig behandling och socialt stöd, ska kunna leva ett fullvärdigt liv. De ska ha sysselsättning och framför allt ha möjlighet att påverka sin egen vardag utifrån egna behov och önskemål (Bachrach, 1992). Den nya viljeriktningen uttryckt i reformen, däremot, riskerar orättvisa bedömningar då det, av de professionella, fordrar en tolkning om vad som t.ex. menas med ett fullvärdigt liv och en meningsfull sysselsättning.

Definitionen psykiskt funktionshinder har formulerats och förankrats i lagstiftning (Regeringens proposition, 1993/94:218). Detta för att på ett rättvist sätt kunna bedöma omfattning av vårdbehov, praktiskt stöd, och omsorg till personer med psykiska funktionshinder för att de ska kunna klara av att leva ute i samhället. Emellertid är det av vetenskapligt intresse att uppmärksamma att definitionen inte är ”evidensbaserad” eller en syntes av resultatet av empiriska studier. Begreppet psykiskt funktionshinder har däremot sin grund i psykiatrireformens socialpolitiska ideologi där normalisering och integrering är nyckelprinciper som i sin tur, i praxis, implicerar vård och omsorg av personer med psykiskt funktionshinder.

Normalitet hör till vardagslivet och kan förstås som naturligt, vanligt, normenligt eller med andra ord hur det bör vara (Israel, 1971; Hansson och Svensson, 1998). Att bedöma vad som är ett normalt beteende hos en person innebär att värdera denna persons beteende (Hansson och Svensson, 1998). Talar vi om att normalisera så innebär det att vi ska anpassa denna person till det vanliga vardagliga, indirekt är denna anpassning en form av maktutövning (a.a.). Normaliseringsprincipen menar Nirje (2003) bör fungera som en färdriktning för vården, pedagogiken och politiken. De grundläggande normaliseringsprinciperna utgår ifrån olika kulturers livsmönster, vardags- och årsrutiner samt de samhällsstrukturer som individer lever i (a.a.).

Detta innebär att människor med psykiska funktionshinder ska normaliseras och återanpassas eftersom de inte följer gängse normer eller regler, då de är avvikande eller onormala (Mallander *et al.,* 1998). Återanpassningen ska ske genom olika stödinsatser såsom ett eget boende, sysselsättning, innehållsrik fritid och psykiatrisk behandling.

Dessa normativa principer styr psykiatrisk vård och motiv till behandling även om uppfattningen om vad som är ”normalt” troligen är tids - och kulturbunden. Vilka ”funktioner” som för tiden är acceptabla kan omtolkas i förhållande till samhällsförändringar. Dessutom finns det en risk att de personer som begreppet berör, betraktas som en homogen grupp oavsett kön, ålder och vilka enskilda behov av stöd de själva anser att de behöver.

En studie av Svensson och Hyltén (1995) om lekmän och deras föreställningar om sinnessjukdom visar på deras svårigheter att beskriva hur ett avvikande beteende kan uttryckas i vardagslivet. Lekmännens beskrivningar utgår från hur de praktiskt ska hantera situationen om de träffar människor med sinnessjukdom och likaväl som hur samhället bör agera. Föreställningarna och beskrivningar om avvikelse handlar inte om kunskaper om psykiatriska tillstånd. Författarna menar att det är viktigt att reflektera över psykiatrins roll när det gäller våra värderingar om önskvärda och oönskade beteenden samt vad som är normalt och icke-normalt (a.a.).

I Sverige har normalisering gjorts till en del i den officiella politiken där normaliseringsbegreppet har blivit legitimt att använda (Mallander *et al.*1998). Vården av människor med psykiska funktionshinder har förskjutits från mentalsjukhus till eget eller alternativt boende (Bülow, 2004). Detta har medfört att sjukhusvården har ersatts med öppenvård, alternativa stödinsatser och olika former av dagvård. Antalet intagningstillfällen har minskat hos dem som tidigare har haft en hög vårdkonsumtion. Bülow (2004) menar dock att människor med psykiska funktionshinder fortfarande lever i marginalen, inte som psykiatriska patienter utan som samhälleliga medborgare i ett socialt utanförskap.

Andra problem som tydliggjorts vid avinstitutionaliseringen är att nedskärningen av sjukhusplatser inte i motsvarande grad har ersatts med vård– och stödinsatser i samhället (Socialstyrelsen, 1 996:1; Socialstyrelsen, 1998: 4; Björkman, 2000; Markström, 2003). En betydelsefull konsekvens av detta är att den psykiska hälsan för personer med psykiska funktionshinder äventyras då inte får den vård- och det stöd de behöver.

Det delade huvudansvaret mellan kommun och landsting, som också var en av psykiatrireformens intentioner, har medfört att personal från olika huvudmän tolkar sina uppdrag på olika sätt och att patienten som är föremål för vård- och stödinsatser hamnar mitt emellan (Björkman, 2000). Stundtals tenderar samverkansfrågorna skymma psykiatrireformens huvudfråga, nämligen att patientcentrera vården eller att patienter ges möjligheter att bli självständiga och autonoma (Hydén, 1998). Hur patienter själva ser på sina möjligheter eller deras önskan om att bli självständiga individer och leva ett fullvärdigt liv i samhället, vet vi däremot lite om.

Att leva ett självständigt liv med psykiskt funktionshinder

Personer med psykiska funktionshinder vill leva ett självständigt liv med egen bostad, arbete och egen försörjning. De vill bli bemötta som en person och inte som en ”mentalpatient” utifrån ett medicinskt perspektiv (Pickens,1999; Bülow, 2004). Till vissa delar är psykiatrireformens intentioner uppnådda, stora skillnader råder dock mellan storstäder och mindre kommuner. Antalet sjukhusplatser och vårdtillfällen har minskat, samhällsbaserade vårdformer har ökat, kommunala stödinsatser har ökat och nya aktörer har kommit in på arenan (boendestödjare). Daglig sysselsättning är fortfarande otillräcklig, 62 % saknar sådan sysselsättning vilket kan innebära en ökad ensamhet och ett mer omfattande utanförskap. De flesta (80 %) psykiskt funktionshindrade bor i egen lägenhet och uppskattar den boendeformen högt, trots att ensamheten kan bli stor (Socialstyrelsen, 1999:1; Burn och Firn, 2005).

Att ha ett eget boende är en del av att må bra och bli jämlik med andra. Inom västerländsk kultur värderas arbete, sysselsättning och fritid som viktiga faktorer för att leva ett fullvärdigt liv. Personer med psykiska funktionshinder önskar ett avlönat arbete som alla andra. 70 % har inget arbete, 15 % av dem har ett avlönat arbete och 15 % skulle kunna ha ett arbete (SOU, 1998:4; Bejerholm och Eklund, 2004).

En intervjustudie, genomförd i Norge, med psykiskt funktionshindrade personer boende i egen bostad visar att de har liten eller ingen kontakt med sina grannar och att deras upplevelse är att de inte är accepterade av sina grannar. De beskriver bostaden som sin ”borg” (Granerud och Severinsson, 2003). Hansson *et al.* (2002), har i en intervjustudie med schizofrena patienter funnit att de som lever i ett gruppboende mår bättre och är mindre ensamma än de som lever i egna lägenheter. En finsk studie (Salokangas *et al.,* 2006) med drygt 2000 schizofrena informanter visar att kvinnorna har en bättre psykosocial funktion än männen och att de som levde i egen lägenhet med partner mådde allra bäst.

Ett arbete är inte enbart en möjlighet till inkomst och försörjning, det innebär även en möjlighet till att bli aktiva sociala medborgare (Champney och Dzurec, 1992; Reberiro och Allen, 1999). En annan aspekt som Eklund *et al.* (2001) belyst är sambandet mellan upplevt välbefinnande och arbete. Det har visat sig att de som har ett arbete även har en bättre hälsa och välbefinnande. Detta innebär att det är nödvändigt att personer med psykiska funktionshinder har någon form av daglig sysselsättning, även om de inte kan ha eller ges möjlighet att ha ett avlönat arbete.

Inom socialtjänsten finns flera olika dagliga sysselsättningar, en del karaktäriseras som en form av arbete och andra som fritidssysselsättningar. Det gemensamma för dessa aktiviteter är att de är oavlönade och att de vänder sig till specifika grupper med människor med specifika behov.

Sysselsättningsverksamheterna har olika benämningar som arbetsformer inom den dagliga verksamheten, arbetsträning är en vilket t.ex. innebär arbete i trädgård, bageri, restaurangkök, sy- eller metallverksamhet. Benämningar som skyddad verkstad, klubbhus och arbetsfokuserat uppsökande arbete används också (Burn och Firn, 2005). En studie som undersökt arbetsträningsverksamheternas effekter och möjligheter för personer med psykiska funktionshinder att få en anställning och ett arbete uppvisar ett dystert resultat. Deltagande i en arbetsverksamhet förenklar inte situationen, istället försvårar det deltagarnas möjligheter att kunna få ett arbete (Crowther *et al.,* 2001).

Ivarsson (2002), visar i en studie om upplevelser av arbetsterapi, att psykiskt funktionshindrade har en begränsad förmåga att prestera. Detta beskrivs som initiativlöshet, bristande förmåga till problemlösning samt oförmåga att använda tiden rätt. Ivarson (2002) menar att dessa faktorer kan vara en effekt av bristande intresse för uppgiften eller att psykiskt funktionshindrade har stora behov av assistans.

Personer med psykiska funktionshinder som saknar arbete och sysselsättning följt av ett reducerat socialt nätverk, dålig ekonomi och avsaknad av eget boende tenderar att passiviseras. Deras vardagssysslor består av småhandlande och televisionen fungerar som ett substitut för sociala kontakter. Matlagning och hushållsgöromål får stå tillbaka för kaffedrickande och rökande av cigaretter (Bejerholm och Eklund, 2004).

Personer med psykossjukdomar har ofta bara en fjärdedel av antalet personer i sitt sociala nätverk jämfört med normalpopulation (Pattisson *et al* 1975). Gemenskapen med de egna föräldrarna är den relation som är vanligast för människor med psykiska funktionshinder varför föräldrarna både blir förälder, arbetskamrat och vän. Studier som visar skillnader mellan personal, föräldrar och patienters uppfattningar om medicinering och behovsinsatser har utförts av Foldemo (2004). Hon påvisar att patienters uppfattningar om detta skiljer sig från personal och föräldrar. Litteraturgenomgång och tidigare forskning visar att personer med psykiska funktionshinder är oförmögna eller har en ovilja att skapa egna relationer. Deras vardag blir ett passivt tillstånd som de lever i ”här och nu” (Socialstyrelsen, 1998:4; Nyström, 1999; Friedrich *et al.,* 1999; Wiklund, 2002; Nyström, 1999; Nyström *et al.*, 2002; Lindell, 2003; Shimitras *et al* 2003; Bejerholm och Eklund, 2004).

SYFTE

Det övergripande syftet med avhandlingen var att med hjälp av personer med psykiska funktionshinder och deras berättelser om deras syn på det dagliga livet, få en djupare förståelse för deras livssituation och därmed kunskap om vilken form av stöd som de kan behöva för att kunna leva ett fullvärdigt liv.

Delarbetenas syfte va/är att få kunskap om hur människor med psykiska funktionshinder:

- upplever sin vardag, samt identifierar eventuella psykosociala hinder för att uppnå en meningsfull tillvaro (Delarbete I)
- ger uttryck för aspekter i det dagliga livet som de upplever är viktiga (Delarbete II)
- på olika sätt uttrycker sin syn på livet (Delstudie III)
- ger uttryck för sin grundläggande hållning till livet (Delstudie IV)
- (Översikt av delstudierna visas i tabell 1)

Tabell 1: Översikt av delstudierna som ingår i avhandlingen

Titel/ Studie I	**Syfte**	**Datainsamling**	**Metoder för analyser och tolkningar**
Psychosocial disadvantages in the lives of persons with long-term mental illness living in Swedish community. *Journal of Psychiatric and Mental Health Nursing 2002, 9: 457-463.*	Syftet med denna studie var att kunskap om hur människor med psykiska sjukdom upplever sin vardag, samt identifiera eventuella psykosociala hinder för att uppnå en meningsfull tillvaro.	Två kvinnor och två män intervjuades vid tre tillfällen med en till två veckors intervall. Varje intervju varade under en timme.	En kvalitativ innehållsanalys användes för att analysera data.
Titel/ Studie II Social and existential alienation experienced by people with long-term mental illness. Scandinavian Journal of Caring Sciences 2005, 19:373-380.	Syftet med denna studie var att få kunskap om hur människor med psykiska funktionshinder ger uttryck för aspekter i det dagliga livet som de upplever viktiga.	Deltagande observationer med 23 individer från två arbetsverksamheter samt intervjuer med sex kvinnor och två män. Intervjuerna varade mellan en½ och 1½ timme.	En kvalitativ innehållsanalys, samt hermeneutisk tolkning användes för att analysera intervjuerna och fältanteckningarna som inhämtats under observationerna.
Titel/ Studie III Variation in views on life of persons with long-term mental illness. Inskickad	Syftet med denna studie var att få kunskap om hur människor med psykiska funktionshinder på olika sätt uttrycker sin syn på livet.	Fem kvinnor och tre män rekryterades från tre arbetsverksamheter och tillfrågades om de var intresserade av att fotografera föremål, situationer och personer som var viktiga för dem. Fotografierna utgjorde utgångspunkt för en dialog mellan forskare och deltagare.	Analysen följer faserna i den hermeneutiska processen, naiv läsning, strukturell analys och holistisk tolkning av deltagarnas syn på livet.
Titel/ Studie IV Cautiousness- a basic attitude towards life of persons with long-term mental illness living in community. *Inskickad*	Syftet med denna studie var att få kunskap om hur människor med psykiska funktionshinder ger uttryck för sin grundläggande hållning till livet.	Fem kvinnor och tre män rekryterades från tre arbetsverksamheter och tillfrågades om de var intresserade av att fotografera föremål, situationer och personer som var viktiga för dem. Fotografierna utgjorde utgångspunkt för en dialog	Fotografierna tolkades utifrån livsåskådningens tre komponenter, vilka bildade en matris, som ligger till grund för analysen av intervjuerna. Analysen följer faserna i den hermeneutiska processen, naiv läsning, strukturell analys och holistisk tolkning av deltagarnas syn på livet.

TEORETISKT PERSPEKTIV

Det initiala och övergripande syftet med avhandlingen var att med hjälp av personer med psykiska funktionshinder och deras berättelser om deras syn på det dagliga livet, få en djupare förståelse för deras livssituation och därmed kunskap om vilken form av stöd som de kan behöva för att kunna leva ett fullvärdigt liv. Resultatet i den första delstudien visade att det dagliga livet hos informanterna som ingick i studien kännetecknades av en social ensamhet och att informanterna upplevde ett existentiellt tomrum. För att precisera vad de existentiella frågorna handlade om och deras inverkan på det dagliga livet hos personer med psykiska funktionshinder har Jeffners teori (1998) om livsåskådning använts för att tydliggöra de existentiella frågeställningarna i de fortsatta delstudierna.

För att beskriva tankar om grundläggande livsfrågor som människor med psykiska funktionshinder uttrycker och som kan ha betydelse för vårdandet, har i denna avhandling ett tvärvetenskapligt möte mellan vårdvetenskap och livsåskådningsvetenskap kommit till stånd.
Inom både vårdvetenskap och livsåskådningsvetenskap ses människan som en meningsskapande varelse. Vårdvetenskapens kunskapsintresse är hela människan och de behov som uppstår vid ohälsa och sjukdom. En helhetssyn på människan innefattar fysiska, psykiska, sociala och existentiella dimensioner i samspel med varandra (Dahlberg *et al.,* 2003). Livsåskådningsvetenskapen söker gestalta människors frågor om livets mening, vad som är viktigt i livet, vilka skillnader som råder

mellan djur och människor samt existensen och det icke existerande (Bråkenhielm, 2001; Jeffner, 1998).

Vårdvetenskapliga utgångspunkter

Vårdvetenskapens intresseområde är människan, hälsan världen/omgivningen samt vårdandet.

Dessa konsensusbegrepp utgår alltid från patientens perspektiv. Patientens perspektiv har alltid företräde och måste särskilt beaktas (Dahlberg *et al.*, 2003). I denna avhandling utgör människans livsvärld och hennes verklighetsuppfattning den ontologiska eller meningsbärande grunden. Vårdvetenskapens kunskapsintresse och metodologi ställs i relation till helhetssynen på människan.

I livsvärlden är människor tillsammans och kommunicerar med varandra genom språk och föremål (Bengtsson, 1999). Vidare menar Bengtsson att människan är ett kroppsligt subjekt vilket innebär att en människa är en helhet och inte delbar i kropp och själ, dualismen existerar inte inom vårdvetenskapen.

Inom vårdvetenskapen betonas mötet med patientens livsvärld vilket gör att vårdaren möter patienten och dennes kroppliga och själsliga svårigheter. Vårdaren har till uppgift att stödja patientens välbefinnande och lindra patientens lidande (Dahlberg *et al.,* 2003; Wiklund, 2003).

Ett antagande är att när människor ställs inför svåra livsfrågor som upplevelser av ensamhet och övergivenhet eller upplever att de är oförmögna att påverka sina liv uppstår ett livslidande. Sociologen Seeman (1976) beskriver livslidandet som ett paraplybegrepp som han kallar social alienation. Den sociala alienationen består av komponenterna maktlöshet, meningslöshet, normlöshet, socialisering, kulturellt fjärmande/främlingskap inför andra och främlingskap inför sig själv. Människor med psykiska funktionshinder och deras existentiella frågor handlar såväl om livslidande som sjukdomslidande. Ibland förstärks detta lidande för att vården inte uppfyller kriterierna för god vård. Patientens välbefinnande tillgodoses ej eller så hjälper vården inte till att minska och undanröja patientens sjukdoms- och livslidande. En väsentlig del inom vårdforskning är därför sökandet efter förståelse för patientens upplevelser och erfarenheter.

Livsåskådning

Enligt Jeffner (1988) utgörs en livsåskådning av tre komponenter; teorier om människan och världen, ett central värderingssystem och människans grundhållning. Teorier om människan och världen handlar om vad människor tror och anser om den värld de lever i samt människans förhållande till livet och döden, djur, natur, samhälle, religion, historia och universum i stort (a.a.). Den andra komponenten utgörs av människans värderingssystem, dvs. vad det är som bestämmer vårt liv och handlande och vad som är eftersträvansvärt (Bråkenhielm, 2001). Den första och den andra komponenten brukar beskrivas som centrala livsfrågor och bildar en livsåskådning tillsammans med den tredje komponenten, människans grundhållning, som handlar om på vilket sätt människan förhåller sig till sin omvärld. En människas grundhållning beskrivs som en grundposition utifrån vilken människan ger uttryck för sitt förhållningssätt till världen. Detta kan komma till uttryck som att känna på ett visst sätt, eller att befinna sig i en viss sinnesstämning som t.ex. optimism/pessimism, hopp, tillit, förtröstan eller förtvivlan och misstro (a.a.). Andersson (2006) menar att grundhållningen kan ge svar på frågan hur det känns att leva? De tre komponenterna skapar tillsammans ett mönster av människans tänkande och handlande, och bildar en helhet av människans tillvaro.

Livsåskådningens tre komponenter har använts som utgångspunkter för datainsamling och dataanalys i delarbete III och IV.

DESIGN

Epistemologiska grundantaganden

Epistemologin är en gren inom filosofin som problematiserar kunskapens natur, ursprung och giltighet. Designen på denna avhandling är explorativ - tolkande och är baserad på det epistemologiska antagandet att människor har olika verklighetsuppfattningar, är unika och kunskapsgivande (Melies, 1997). För att uppnå en förståelsekunskap måste det empiriska materialet kunna tolkas med hjälp av en relevant teori som stämmer överens med den specifika vetenskapens paradigm, i detta fall, vårdvetenskapen.

Avhandlingens ansats är influerad av kritisk etnografi (Robertsson och Boyle, 1984; Denzin och Lincoln, 1994; Hammersley och Atkinson, 1995; Pilhammar - Andersson, 1996; Denzin, 1997). Kritisk etnografi har till syfte att belysa faktorer som är värdeladdade och begränsande för individers handlande. Tyngdpunkten vid etnografiska studier är att få en bild av mångfalden och komplexiteten i den företeelse som studeras.

I de studier som ingår i avhandlingen används förutom deltagande observationer och intervjuer, autofotografering som datainsamlingsmetod. Under 1940-talet började Bateson och Mead (1942) att tillämpa fotografering som ett tillägg till observationer inom antropologin. Författarna arbetade i ett team under en tvåårsperiod, där en var fotograf och den andre dirigerade. Efter två år valde de ut 759 foton som klassificerades i olika kulturella kategorier som t.ex. föräldrar och barn vilket sammanställdes till en bok (Harper, 1998). Fotografering är fortfarande en sällsynt datainsamlingsmetod och förekommer framförallt inom socialantropologin där metoden tillämpas för att insamla kulturdata av olika slag (Banks, 1995). Gemensamt för de beskrivna studierna med fotografering som metod är att det är forskaren eller någon annan utsedd som står bakom kameran.

Det som är annorlunda med denna avhandling med fotografering som datainsamlingsmetod är att det är informanterna som står bakom kameran. De ombads att fotografera situationer, individer eller föremål som har betydelse för dem och deras livssituation. Tanken med detta var att minska forskarens kontroll över datainsamlingsmaterialet eftersom människor med psykiska funktionshinder, trots sin självupptagenhet, är oerhört vaksamma på vad andra önskar att de ska göra. Dessutom var det viktigt att informanterna själva fick välja vad de önskade fotografera för att få underlag till en dialog eller ett samtal istället för en intervju.

En viktig metodologisk fråga i denna avhandling handlade om hur livsvärlden hos personer med psykiska funktionshinder skulle kunna synliggöras. Med hänsyn till integriteten hos de personer som ingick i samtliga studier var det betydelsefullt med ett öppet och följsamt förhållningssätt.

I samtliga delstudier används kvalitativa datainsamlingsmetoder där informanternas upplevelser och perspektiv inhämtas med hjälp av intervjuer, fotografier och deltagande observationer. Den tvärvetenskapliga ansatsen innebär att berättelser om informanternas livssituation användes som beskrivande data som senare analyserats mot bakgrund av vårdvetenskapen och livsåskådningsvetenskapen.

ETISKA ÖVERVÄGANDEN

Inför samtliga studier i denna avhandling har de medverkande informanterna fått såväl skriftlig som muntlig information om syftet med studien samt innehåll och omfattning av studien. De garanterades också att varken de själv eller den enhet där de uppehöll sig om dagarna skulle kunna identifieras i studierna. Informanterna blev också informerade om att deras deltagande i studien var frivilligt och att de när som helst hade rätt att avbryta sin medverkan. Det material som samlades in genom intervjuer, deltagande observationer, fältanteckningar samt i form av fotografier skall garanteras sekretess och konfidentialitet. Detta innebär att allt datamaterial som insamlades under de fyra delstudierna förvaras på ett sådant sätt att det inte kan komma någon obehörig till del.

Kvale (1997) menar att det är viktigt som forskare att upprätthålla en balans mellan att vara alltför detaljerad i sin undersökning och att utelämna information som kan vara viktigt. Frågor om identitet och integritet kan vara svåra att hantera, särskilt om forskningen bedrivs på enheter, platser eller i andra sammanhang med ett begränsat antal personer och där de medverkande i studien skulle kunna gå att identifiera. I samtliga studier i denna avhandling har datamaterial insamlats genom intervjuer, vilket kräver en nära kontakt med intervjupersonen, i detta fall personer med psykiska funktionshinder. För att över huvud taget kunna etablera en nära kontakt med personer med psykiska funktionshinder krävs i det flesta fall tid men också en försiktighet i sitt närmande samt känsla och förståelse för denna grupp personers utsatthet.

Kvale (1997) menar att i den nära kontakten mellan forskare och intervjuperson är det forskarens skyldighet att skydda informanterna från skada. Kvale menar också att det åligger forskaren att vara lyhörd vad gäller de frågor han/hon ställer under intervjun. Att använda citat för att belysa händelser, situationen, men också för att styrka en gjord tolkning är vanligt förekommande i kvalitativa studier och ingår också i studierna i denna avhandling. Användningen av citat i forskningssammanhang har diskuterats bland annat på grund av risken för att citatet skulle kunna leda fram till en identifiering av informanten.

Detta har särskilt uppmärksammats i dessa studier då antalet medverkande är relativt få och antal verksamheter där studierna bedrivits begränsade.

Deltagande observation har varit en form av metod för insamling av datamaterial, som inte varit helt lätt att genomföra. Att som deltagande observatör, utifrån informanternas perspektiv, sitta passiv, relativt tyst och oåtkomlig har i vissa situationer framkallat negativa känslor hos informanterna, såsom misstänksamhet, irritation och oginhet. Genom att utföra en mindre uppgift som att stryka eller nåla ett tygstycke kunde forskaren bättre smälta in i gruppen och blev därmed inte bli lika hotfull som tidigare. En annan viktig etisk fråga i detta sammanhang är hur forskaren skall förhålla sig till informanternas försök att inleda ett samtal. En avvisande attityd från forskaren kan innebära att informanterna känner sig kränkta.

I två av studierna utgör fotografier en del av datamaterialet. Av vad som framkommit har denna modell för datainsamling bemötts positivt av informanterna, det har även inneburit att insamlad data är baserad på vad informanterna själva valt att berätta om. Fotografierna utgör dock ännu ett etiskt dilemma då föremål, personer och platser ofta lätt går att identifiera även för personer som befinner sig utanför den grupp som har med forskningen att göra. Forskaren kan heller inte vara säker på att de personer som förekommer på fotografiet har givit sitt samtycke till detta.

Godkännande av samtliga studiers genomförande inhämtades från stadsdelsdirektör i berörd stadsdelsnämnd som kom att bli aktuell för datainsamling. Godkännande inhämtades även från chefsöverläkare inom aktuellt upptagningsområde. I studiens initialskede fungerade en ansvarig chef inom kommunal verksamhet som ”gatekeeper” (Pilhammar - Andersson, 1996). Denna person var mig behjälplig i kontakten med den verksamhet inom vilken datainsamlingen genomfördes. Presumtiva informanter informerades och tillfrågades skriftligt och muntligt om sitt deltagande.

Samtliga studier har granskat av den Regionala etiska kommittén vid Karolinska Universitetssjukhuset, Stockholm, Sverige: **Studie I** Reg.nr. 99-019; **Studie II** Reg.nr. 55/02; **Studie III** och **Studie IV** Reg.nr. 2004/5:9.

SAMMANFATTNING AV DELSTUDIERNA

Studie I

Urval

Urvalet av informanter till Studie I var personer med psykiska funktionshinder i ålder mellan 30 och 65 år. Vid tidpunkten för studien var samtliga boende i egen lägenhet i kommunen. Samtliga hade kontakt med såväl den psykiatrisk vård som social service. Personal i psykiatrisk öppenvård var behjälpliga i rekryteringen av patienter. Två män och två kvinnor uttryckte sitt skriftliga samtycke till att delta i studien och att bli uppringda av forskaren för en överenskommelse om tid och plats för en intervju. Intervjuerna genomfördes i informanternas hem. Ett intervjutillfälle förlades till en annan plats därför att informanten bedömde lägenheten som alltför stökig.

Avsikten med intervjuerna var att utvinna beskrivningar som utgick från intervjupersonernas livsvärld för att därefter tolka innebörden av dessa. Under intervjuerna användes temaområden som utgick var möjliga att förändra och anpassa under intervjuns gång. Intervjuerna kan karaktäriseras som en form av samtal (Kvale, 1997). Det är emellertid viktigt att påpeka menar Kvale (1997) att den personliga närhet som råder under en intervju också ställer höga krav på intervjupersonens lyhördhet, att beakta huruvida han/hon skall gå vidare eller inte vid varje moment av sin utfrågning. Att få tillgång till en människas livsvärld förutsätter en öppenhet, som innebär att forskaren är mottaglig för ny kunskap, samt har kunskap om sin egen åsikt i ämnet (Kvale, 1997; Dahlberg *et al.,* 2001).

Informanterna intervjuades tre gånger med en till två veckors intervaller. Den tredje intervjun var kortare än den första, men varje intervju varade ca 1 timme. Tanken med uppföljande intervjuer var att fånga processen, få fler nyanser och kontrollera forskarens egen förståelse samt öka graden av validitet (Lipson, 1991; Svedberg, 2003).

Tidsintervallet gav informanterna möjlighet till att reflektera över tidigare intervju, samt vid behov komma med förtydligande, tillägg eller rättelser. Den första intervjun började med att forskaren bad informanten att beskriva hur vardagen såg ut med hjälp av en intervjuguide som handlade om informantens livssituation, stöd, service och dagliga aktivitet. Intervjutillfälle två och tre inleddes med att fråga om informanten hade reflekterat över den tidigare intervjun och om de önskade berätta om något ytterligare. Därefter summerades tidigare intervju av forskaren och återgavs till informanterna. Intervjutekniken var sonderande, informanternas uttalanden summerades eller upprepades, för att ge informanten möjlighet att korrigera eller utveckla vad de tidigare berättat (Winter, 1978; Patel, 1987; Svensson och Starrin, 1996; Kvale,1997). Intervjuerna spelades in på band efter informanternas samtycke.

Dataanalys

Samtliga tolv intervjuer i **Studie I** skrevs omgående ut till text efter varje möte. En kvalitativ innehållsanalys (Sandelowski,2000) användes för att identifiera teman som beskrev aspekter i det dagliga livet, aktiviteter, erhållit stöd samt personliga erfarenheter (Denzin och Lincoln, 1998). Varje intervju lästes igenom flera gånger för att dels få en uppfattning om innehållet i varje intervjun, dels få en känsla av innehåll av det totala materialet. Därefter lästes och noterades innehållet i texten mening för mening med avsikt att identifiera väsentliga faktorer i relation till hur informanterna upplever sin vardag. De framtagna kategorierna jämfördes därefter med varandra med avsikt att reducera materialet och bilda teman. Förslagen på teman diskuterades och jämfördes av samtliga forskare med avsikt att validera studien (Baxter, 1991). Genom denna interna valideringsprocess utvecklade forskarna en djupare förståelse för de psykosociala svårigheter som personer med psykiska funktionshinder upplever i livet.

Resultat

Studien har utmynnat i tre teman som belyser psykosociala begränsningar i det dagliga livet;

1/ känsla av ensamhet men oförmåga att initiera och skapa vänskapsrelationer 2/ kunskap om behov men bristande initiativförmåga 3/ behov av stöd men vill inte bli kontrollerad

Känsla av ensamhet men oförmåga att initiera och skapa vänskapsrelationer

Detta tema refererar till bristen av sociala relationer. Samtliga informanter berättade att de hade vänner som barn men när de blev sjuka så förändrade detta sig och ”grubblerierna” började. Informanterna har under en lång tid haft ett begränsat nätverk men de visste inte hur de skulle kunna skaffa vänner eller vad vänskap var. Deras långvariga sjukhusperiod hade försatt dem utanför de sociala arenorna. Informanterna var medvetna om och hade varierande insikt om orsakerna till sin sociala isolering men angav att de inte hade förmåga att påverka detta. De ansåg det nödvändigt att ha vänner och att intressera sig för andra människor. Alla informanter berättade att de hade rösthallucinationer när de var ensamma. Alla informanter har rutiner i det dagliga tillvaron och de människor de möter är inga som de känner att de kan skapa goda relationer med. De professionella som kommer till deras hem är inga som de kan bli vänner med. Sjukhusvistelsen, däremot, minskar ensamhetskänslan eftersom den ger möjligheten till möten med andra människor.

Kunskap om behov men bristande initiativförmåga

Detta tema handlar om informanternas berättelser om känslan av maktlöshet och förmåga att ta initiativ för att reda ut livet. Samtliga informanter ville ha ett jobb som de menar är viktigt för hälsan. Emellertid varierar deras inställning till arbete eftersom de har svårt att klara av ett arbete – trots att de ansåg att arbete vore meningsfullt, särskilt för att kunna träffa andra människor. Däremot berättade ett flertal att det var svårt att ta sig upp på morgonen.

Anser sig vara i behov av stöd men vill inte bli kontrollerade

Informanterna möter ca 15 professionella som är involverade i planering av deras liv. De anser sig vara behov av dagligt stöd och aktivitet men vill inte bli kontrollerade. Informanterna menar att socialtjänstpersonalen har en vitalt inflytande på deras liv och känner sig säkrare eller tryggare tillsammans med socialtjänstpersonalen. Personal som ger dem beröm gör att de kan klara av svåra saker.

Däremot, berättade informanterna, att de ställs utanför planeringen av deras behandling och rehabilitering eller vad de ska göra för att ha ett meningsfullt liv. Även anhöriga tar över och planerar för informanternas men det har inte bara negativa sidor eftersom de ger möjlighet till sociala kontakter uttryckt som ”det är åtminstone någon som kommer”.

Studie II

Urval

Datainsamlingen för Studie II var förlagd till två skilda arbetsverksamheter, förbehållna personer med psykiska funktionshinder. Insamling av data har skett dels genom deltagande observationen av tjugo kvinnor och tre män dels genom individuella intervjuer med sex kvinnor och två män. Intervjupersonerna var mellan 21 och 57 år. Forskaren beskrev syftet med studien för instruktören på arbetsverksamheten och presumtiva informanter informerades såväl muntligt som skriftligt om studien. Ytterligare möten ägde rum där forskaren tillsammans med de presumtiva informanterna diskuterade möjligheter och förutsättningar för att genomföra studien. Det var viktigt för de presumtiva informanterna att få garanti för att observationsmaterialet inte skulle komma att missbrukas. Det var också viktigt att planera tiden för kommande observationer så att de personer som inte önskade delta i observationerna inte var närvarande på arbetsverksamheten.

I etnografiska studier är det inte vanligt att i förväg besluta om hur många informanter som bör ingå (Denzin och Lincoln, 1994; Hammersley och Atkinson,1994; Pilhammar - Andersson, 1996). Tyngdpunkten vid etnografiska studier är att få en bild av mångfalden och komplexiteten i den företeelse som studeras.

Deltagande observationer var den huvudsakliga metoden för datainsamling i denna studie. Semistrukturerade intervjuer har tillämpats i anslutning till deltagande observationer.
Intervjuerna fokuserades på områden som av forskaren upplevdes som oklara under observationerna. Observationsstudierna genomfördes under två månader fördelade på två perioder om två veckors intervall. Varje observationstillfälle varade ca 4–6 timmar.

Observationerna baserade sig på ett i förväg utarbetat observationsschema som handlade om integrationer och kommunikationer informanter emellan och instruktörer under arbete och på kaffestunder och luncher. Dessutom innehöll observationsschemat informanternas arbetsinsatser, närvaro och verksamhetens grupprocesser.

I början intog forskaren en passiv observationsroll i perioder av intervaller om 15-20 minuter, för att däremellan gå undan för att göra anteckningar. Efter ett par dagar förändrades observationsrollen, då några av informanterna uttryckte sin oginhet samt misstänksamhet och irritation mot forskaren. I syfte att inta en mindre störande observationsroll förändrade forskaren sin närvaro till att delta i verksamheten i form av att utföra ett enkelt arbete. Ovanstående förändring av observationsrollen innebar att klimatet och kommunikationen mellan informanterna förändrades till det positiva.

Under den andra observationsperioden möttes forskaren av ett mer öppet välkomnande.

Observationsmaterialet insamlades genom fältanteckningar. Intervjuerna omfattade 20 till 60 minuter och genomfördes i enhetens samtalsrum eller uppehållsrum. Samtliga intervjuer bandades utom en på informantens önskan. Fältanteckningar nedtecknades till berättelser och bandade intervjuer nedtecknades ordagrant. Vid textöverföring avidentifierades samtliga datamaterial.

Dataanalys

Tillvägagångssättet för att analysen av datamaterialet i **Studie II** som består av såväl transkriberade intervjuer som fältanteckningar är detsamma som i **Studie I.** Den första fasen av analysen innebar att identifiera likheter och olikheter som informanterna upplevt vara ett hindrat för dem att leva ett aktivt liv. Det framtagna analysmaterialet sammanställdes till teman och subteman. Nästa fas bestod av att identifiera mer eller mindre bakomliggande innebörder i det framtagna datamaterialet. Det preliminära resultatet omarbetades till sex preliminära tolkningar.

Det är svårt att ha ett aktivt liv;

1/ När man inte vet vem man är i relation till andra, 2/ När man inte kan förutse något om framtiden, 3/ Det är inte lätt när man brister i kunskap och inlärningsförmåga, 4/ När ens minnen och erfarenheter framförallt består av svårigheter, 5/ När man är oroar sig över orsakerna till sin sjukdom, 6/ När det svårt att intressera sig för andra.

Resultat

När man inte vet vem man är i relation till andra

Flera informanter säger att de inte känner sig säkra på vilka de är i relation till andra människor. En del informanter upplever inte heller att de är riktigt godkända som fullvärdiga deltagare av en gemenskap eller delaktiga i en medborgerlig samvaro. När de deltar i någon form av verksamhet känns det inte som de är där på samma villkor som de övriga deltagarna.

> Jag känner mig som ett original när jag är tillsammans med andra.
> Jag har lätt för att få kontakter och vill inte vara en enstöring.
> Det känns som om man inte passar in.

Utanförskapet ser ut att vara en aktiv handling. Några informanter talar om sig själva som udda och annorlunda. De jämför och värderar sig själva, och finner att de inte alltid duger, men också att deras originalitet är unik. Jämförelser med andra leder alltså till två lite motsägelsefulla förhållningssätt. Informanterna upplever dels att kommer till korta, men också att de inte är några dussinmänniskor. Därför blir de ofta trötta på andra människor som klarar av att vara dussinmänniskor. Emellertid, informanterna anstränger sig att få uppmärksamhet av instruktörer, förmodligen för att det är väldigt svårt att bli uppskattade av andra deltagare i den dagliga verksamheten. Fältanteckningarna belyser att hur informanterna försöker få kontakt med andra;

> Informanterna försöker att få igång en konversation med instruktörerna genom att tala om radioprogram och tidningsartiklar.

En ambivalens genomsyrar informanternas berättelser å ena sidan vill de vara i blickfånget å andra sidan vill de få intresset riktat mot sig. Ett hinder för att leva ett aktivt liv förefaller vara att personer med psykiska funktionshinder är osäkra om vem de är i förhållande till andra.

När man inte kan förutse något om framtiden

Kontinuitet och förutsägbarhet är nödvändigt för att informanterna skall kunna ha ett socialt liv.

I förutsägbarheten ingår en längtan efter egen inkomst, eget arbete och rutiner. Detta skulle kunna göra informanterna oberoende och öka deras självständighet. Att kunna planera sin framtid är också ett viktigt sätt att få makt över sig själv och sin egen livssituation.

> Det är viktigt att ha en egen inkomst, jag vill ha min egen försörjning.

Emellertid, när målen är för högt satta förstärks känslan av svaghet hos informanten. Till exempel, målet att ha en inkomst kan bli för stor när informantens ambitioner inte står i samklang med deras brister. Framförallt, deltagarna i denna studie visar att de är rädda för att planera något som de skulle misslyckas med. De uttrycker sin rädsla och hopplöshet med att det är meningslöst för det går ändå inte att påverka och väljer således att inte göra något alls.

> Jag har inga tankar och önskningar, jag bryr mig inte.
>
> Jag tycker att jag kan ta beslut men dagarna ser ändå ut som dom gör.

Behovet av förutsägbarhet tycks alltså leda till negativa förväntningar. Den som är inställd på att misslyckas behöver ju inte bli besviken när misslyckandet väl kommer. Som ett resultat, ett hinder för ett aktivt liv tycks vara när informanterna finner det svårt att fundera om framtiden.

Det är inte lätt när man brister i kunskap och inlärningsförmåga

Flera av informanterna säger att de har förlorat sådan kunskap som de tidigare haft, och att detta i sin tur har med deras psykiatriska problem eller behandling att göra. Det är svårt för dem att inhämta både kunskapsförluster och den nya kunskap som yrkeslivet kräver. Många informanter vill lära sig det de behöver för att kunna fungera som aktiva samhällsmedborgare, men de upplever att de har begränsad inlärningsförmåga, som kan göra det svårt att tillgodogöra sig de reguljära utbildningsprogrammen.

> Jag vill gå gymnasiet men det måste vara långsam studietakt.
>
> Mitt minne är dåligt det fastnar inget, jag är orolig för det. Minnet är viktigt!
>
> Svårt att veta men det kanske beror på medicinerna?

Att drabbas av att minnet sviktar och att tidigare kunskaper försvinner är mycket oroande. Detta ger en osäkerhet och försvårar möjligheten att leva ett aktivt liv.

När ens minnen och erfarenheter framförallt består av svårigheter

Samtliga informanter beskriver att nuvarande situation har ett klart samband med deras tidigare erfarenheter och från deras uppväxt. För några av dem, har flera tragedier inträffat samtidigt, samt att de inte känt sig omtyckta av andra. Dessutom, några uttrycker att de har svårt att bedöma konsekvenserna av sitt handlande. Informanterna är väl införstådda med vad hindren består av men de har svårt att ta itu med sina svårigheter.

> Mina föräldrar dog när jag låg i skilsmässa samtidigt som jag var delaktig i en trafikolycka.
> Jag har aldrig fått höra att jag är bra på någonting.
> Jag har alltid haft svårt att göra mig hörd.
> Tidigare olösta problem blir ett hinder för att komma vidare.

När man är oroar sig över orsakerna till sin sjukdom

Informanternas bristande kunskap om sin psykiska sjukdom kan bli ett ytterliggare hinder för att leva ett aktivt liv.

> Jag vill ta reda på vad mina föräldrar säger om min sjukdom och inhämta mer kunskap om min sjukdom.
> Att få en diagnos kan ge en befrielse.

När det svårt att intressera sig för andra

Flera av informanterna ger uttryck för ointresse av att ha kontakt med andra. Andra människor ger dem inga stimuli och informanterna har inga tankar eller tilltro om sig själv att kunna ge något till andra.

Informanterna är inte särskilt aktiva till att ta kontakt med andra människor, framförallt med instruktörerna.

> Jag kanske inte är intresserad av att umgås.
>
> Jag känner mig tom, allt är jobbigt!
>
> Passar inte in – det spelar ingen roll vad jag gör.

Följaktligen, informanterna menar att de alltid haft svårt för att etablera relationer framför allt med det motsatta könet. Dessutom vill de inte umgås med människor som har liknande svårigheter som dem själva. Deras initiativ till kontakt förefaller vara förbundet med något som de behöver, i annat fall avstår de.

Att skapa relationer förutsätter att aktivt rikta intresset mot någon annan än sig själv och ibland ge upp sina normer och värderingar för hur relationer skapas. Informanterna avstår från nya kontakter och i stället fortsätter de med att skydda sig så att deras heder eller värderingssystem inte påverkas, samtidigt som de talar om ett utanförskap.

> Jag har alltid haft det svårt att umgås med andra.
>
> Jag kanske inte vill dra in dem i min värld.
>
> Jag har svårt att småprata.

Svårigheter i att utveckla intresse för andra människor verkar sålunda bli ett hinder för att skapa gemenskap med andra för ett aktivt liv.

Studie III och Studie IV

Urval

Datamaterialet som består av intervjuer och fotografier är desamma för **Studie III** och **Studie IV.** Deltagarna bestod av fem kvinnor och tre män, som samtliga uppfyllde kriterierna för att delta i studierna. Informanterna rekryterades från tre arbetsverksamheter för personer med psykiska funktionshinder. Arbetsverksamhetens instruktörer var " gate- keeper " och förmedlade en skriftlig information om studierna till potentiella deltagare. Handledarna var också behjälpliga med att arrangera informationsmöten, samt lokal för möten mellan forskaren och individuella informanter.

Samtliga informanter fick en engångskamera och ombads att fotografera situationer, föremål och individer som var betydelsefulla för dem. Ett par av informanterna hade av olika anledningar inte hunnit med att ta de fotografier de önskade under den aktuella veckan, varför tiden förlängdes ytterligare. Vid alla tillfällen utom ett hade engångskamerorna förberetts genom att trycka bort fotografier så att det endast fanns 13 bilder kvar. De flesta tog ett 10-tal fotografier som överenskommet var utom en person som tog 23 bilder. En annan av informanterna hade av misstag låtit kameran komma i händerna på sina barn, som lyckades förstöra den. En annan av informanterna hade inte lyckats med att ta fler bilder än sju på grund av att det var så svårt att välja motiv.

Skillnaderna i antal fotografier uppfattas inte som att det har haft någon större betydelse för intervjuerna eftersom flera av informanterna har lagt ned ett stort arbete på att göra de rätta urvalen av sina fotografier, d.v.s. som överensstämmer med deras uppfattning om vad de vill berätta. De informanter som endast tagit ett mindre antal fotografier har in stället bidragit med mycket innehållsrika berättelser. Däremot gav den informant, som tagit flest fotografier, en mer ytlig och generell berättelse om de olika fotografierna.

Intervjun inleddes med att forskaren överlämnade dubblerade fotografier till informanterna. Samtliga informanter tittade på fotografierna, en del la ut fotografierna på bordet, andra satt med dem i handen. Varje informant ombads att berätta om sina fotografier. Några av informanterna förväntade sig att forskaren skulle välja ut fotografierna, men med en försiktig uppmuntran valde så småningom ut de fotografier de önskade berätta om, samt i vilken ordning detta skulle ske. De flesta av informanterna hade redan under fotograferingen bestämt sig för i vilken ordning de önskade berätta om fotografierna de tagit. När informanterna valt ut sina fotografier ställde forskaren frågan ”kan du berätta om denna bild”?

Samtliga intervjuer, som pågick drygt en timme, bandades. Forskaren träffade två av informanterna vid två intervjutillfällen, då dessa informanter önskade ta ytterliggare ett par fotografier eftersom de saknade några vinjetter som de önskade ha med.

Studie III

Dataanalys

Hermeneutisk tolkning

Den första preliminära databearbetningen innebär en strukturering och renskrivning av datamaterialet. Därefter kodas (innehållsanalys) materialet utifrån ord, fraser eller delar av text relaterat till de frågeställningar som är relevanta för forskningens syfte. De erhållna koderna, som ska ge svar på frågeställningarna grupperas utifrån likheter och olikheter till kategorier. I nästa steg undersöks sambanden mellan de framtagna kategorierna som sammanställs till teman (innebördsanalys). Med hjälp av tolkning, söks en djupare innebörd i temat, i syfte att förklara livsåskådningen och dess betydelse för personer med psykiska funktionshinder och deras livsvillkor relaterat till hälsan och aktivitetsförmågan.

Resultat

Fyra teman framkom; 1/Tankar om Gud, meningen med liv och död, 2/Meningen med relationer till andra, 3/Djur ger livet mening utan fordran, 4/Föremål och dess symboliska mening för livet.

Tankar om Gud, meningen med liv och död

Detta tema beskriver informanternas tankar om meningen med livet och vad som händer efter döden. ” Att tro ger livet en mening” som en informant sa ” det gör mig friskare och säkrare”. ”Det är livet som ger sjukdom, ingen föds med en psykiatrisk sjukdom”. Informanterna berättar om en sorts andlighet som inger lugn och frid och som enbart uppstår i livets början och slut. Andligheten representerar för informanterna en sorts renhet, där inga sjukdomar finns. Däremot är döden skrämmande för informanterna. Informanterna beskriver en rädsla för att dö, ”att försvinna bort från jorden och att allt tar slut”. Att inte finnas längre betyder att bli ”utplånad - ingen kommer att minnas dem och de blir bortglömda” som en informant sa. Andra säger ”det är lika bra att bara försvinna, att inte ha någon grav och gravsten, ingen kommer ändå att besöka den då jag är så betydelselös”. Men att ha en grav som andra skulle kunna besöka, menar en annan informant, ger en liten möjlighet att bli ihågkommen, trots känslan av att vara betydelselös.

Informanternas beskrivning av sina känslor av ensamhet är stor och risken för att bli bortglömd skapar dödsångest hos dem. Det är viktigt enligt informanterna att finna någon sorts mening med sitt liv innan man dör. Om meningen med livet förblir ouppklarat är det svårt att finna en fridfull död. En önskan om ett evigt liv eller tron på ett liv efter döden skulle kunna ge dem en möjlighet att någon gång bli ”sedd”.

Att ha en tro på Gud är viktigt trots att informanterna känner sig svikna av Gud då Han faktiskt inte funnits för dem när de som bäst behövt Honom. I stället, upplever de att Gud har bestraffat dem och ratar dem. En informant menade att detta kan vara en anledning till att söka en annan tro. En annan informant sa, ”Du kan inte vara utan en tro, därför det kan leda till självömkan och ett kortare liv”. ”Att vara ateist är självutbrännande.”

Dessa exempel på informanternas tankar indikerar att livet har en mening, men meningen med livet är inte att bli religiös. Dessutom, ingen är född med en psykisk sjukdom

Meningen med relationer till andra

Informanterna upplever att deras liv hade kunnat vara annorlunda framförallt om deras föräldrar hade varit harmoniska, när de var barn. Idag hade de haft ett bättre självförtroende och tillit till andra människor. En av informanterna menar att om hennes mamma hade haft en ”skyddsängel” så hade hon varit ”gladare” och då hade informanten inte behövt känna sig så ”trasig, som hon menar schizofrena människor känner sig.” Informanterna söker finna en form av försoning med sina upplevelser från tidigare liv och relationer till föräldrar för att finna en mening med sitt nuvarande liv. Informanternas erfarenheter av relationer med andra människor är ofta förenat med misstänksamhet. De menar att de ”umgåtts med fel folk” eller att de har dåliga erfarenheter av människor. Alla informanter menar att de hellre relaterar till djur än till människor, då de känner sig lugnare och fredligare med djur. Deras syn på djur är att dessa har samma värde som människor.

Djur ger livet mening utan fordran

Detta tema handlar om informanternas beskrivningar om och relationer till djur. Djur (husdjur) ger livet en mening, menar informanterna, och har samma värde som människan. En informant betonar starkt, ”alla borde av moraliska skäl bli vegetarianer”. De flesta av informanterna upplever att det är lättare att vara tillsammans med djur än med människor, därför att husdjur är, ”kravlösa mot människor, djur är mer lojala och anpassar sig efter människan och hennes behov och hälsotillstånd”. En konsekvens av detta är, ”djur har ingen fordran på någonting samtidigt som de är följsamma” och ”jag upplever att min omsorg besvaras med tillgivenhet”. Informanterna beskriver att ett ömsesidigt välbefinnande då uppstår mellan djuret och människan. En vältalig informant beskriver deras relation som ”om jag inte fungerar, då fungerar inte mitt husdjur – han slutar upp med att leka och visar inte upp någon glädje heller så blir han nedstämd”.

De meningsfulla relationer som informanterna har är med sina husdjur. Relationen existerar så länge informanterna lever, vilket betyder att de minnen informanterna har av sitt liv inte kan bäras vidare. Det är en kulturell aktivitet som deras husdjur inte är i stånd att bära vidare. Deras husdjur kan varken överföra sorg eller glädje även om de har känslor.

Föremål och dess symboliska mening för livet

Detta tema beskriver de föremål som informanterna fotograferat och vilken betydelse dessa har för informanternas liv. Informanternas brist på kontakt med andra människor medför att ingen finns att tillgå som symbol bärare. Bristen på tillit till andra människor försvårar tillvaron ytterliggare för informanterna då ingen är ”god nog” för att ärva deras värdefulla föremål. Informanterna talar om föremålen som att de är en del av dem själva. Genom att skänka bort ett föremål skänker informanterna också bort en del av sig själva, vilket naturligtvis ökar kravet på mottagaren.

Föremål kan också vara symboler för att skapa känslor av harmoni. En informant berättar att ”änglar” hjälper henne att ”bli helare”, ”inte så trasig”. Hon säger; ”änglar vill ens bästa”. Symboler, som änglar, kan fungera som en bro till kontakt med andra människor. Att göra inköp och vara ägare av föremål kan upplevas som att vara som alla andra det är att spegla en önskan om att bindas till den materiella världen. Men det är viktigt, menar informanterna, ”föremålen får inte bli för många, detta skapar oordning och kaos”. Datorn kan, t.ex. förmedla kontakt med andra människor, men då på informantens egna villkor.

Studie IV

Dataanalys

Dataanalysen består av en beskrivning av de 97 fotografierna och en analys av de åtta intervjuerna. Dessa strukturerades enligt en matris (fig. 2) som bygger på Jeffners (1998) tre komponenter; människa, djur och natur samt föremål. En modifikation av Jeffners teori är att analysen vill spegla såväl ett inifrån perspektiv som ett perspektiv på omgivningen hos informanterna. Dataanalysen följer i princip faserna i en hermeneutisk process naiv läsning, strukturell analys och helhetstolkning av informanternas basala attityder till livet (Söderberg *et al.*, 1999). Naiv läsning är det första steget i tolkningen. En strukturell analys inkluderar att undersöka delarna i texten till att ta reda vad och hur det uttrycks. Alla informanter har illustrerat sitt dagliga liv; några har tagit självporträtt eller fotografier på sitt hem eller sin familj.

Många fotografier är tagna på arbetsverksamheter och instruktörer. Ett fåtal av fotografierna är arrangerade med personer eller föremål. Några av informanterna har endast fotograferat sitt hem eller sin familj.

Tabell 2. Jeffners livsåskådningskomponenter

	Människa	**Djur och Natur**	**Föremål**
Personlig/ Samhällelig Nivå	Jag själv Närstående (maka/make, barn, släkt, vänner) Andra (arbetskamrater, personal)	Husdjur Fåglar Växter	Interiörer Möbler Hushållsredskap Dator/TV Prydnadssaker Arbetsverksamhet Psykiatrisk mottagning Offentliga byggnader

Resultat

Självporträtt

Tre informanter (kvinnor) har låtit fotograferat sig själva, totalt sju fotografier. Ett av självporträtten visar en kvinna med festfrisyr, välsminkad och iförd en svart paljettklänning.

Det andra självporträttet är en kvinna i 35-årsåldern med cendréfärgat kort hår klädd i T-shirt och arméjeans. Fotot ät taget i ett barnrum, med några teckningar på väggen, vilka föreställer en hund, en sol och en nalle. Informanten står framför en furusäng, med en stol intill som ser ut att fungera som sängbord.

Den tredje kvinnan har tagit fotografier på sig själv, verksam i arbetsverksamhetens lokaler. Informanten har sitt hår uppsatt i en hästsvans och hennes ansiktsuttryck är sammanbitet och ansträngt.

Informanternas berättelse om sig själv i förhållande till fotografierna

Såväl de tre informanterna som låtit fotografera sig själva som övriga fem informanter berättar om sig själv utifrån vad de varit med om, hur de har det och hur de skulle vilja att deras liv utvecklades. De berättar om vad det innebär för dem att ha en identitet, hur en människas identitet formas, vad lidande och välbefinnande betyder, samt vilken betydelse deras tidigare erfarenheters har haft för deras personliga utveckling.

Sökande efter en egen identitet

Den första informanten som klätt sig fin inför fotograferingen berättar: ”Det känns som när jag var liten och klädde ut mig.” ”Jag är kluven till att klä upp mig, det är kul att glittra samtidigt som jag inte vill uppmärksammas.” Hon fortsätter, ”det är inget problem eftersom jag aldrig går på fest eller träffar folk”, informanten söker bli kvinna, vill må bra och känna glädje. Hon vill vakna upp och känna att det fungerar, ”att göra något för mig själv och inte alltid för andra”. En annan informant berättar att det är viktigt att göra saker för sig själv och inte bara för andra. Att ha egna åsikter som skiljer sig från andras är obehagligt.

Det är viktigt för informanterna att göra något av livet, att finna en mening med livet, då livet kan ta slut när som helst. Att bli självständiga, att skapa en inre säkerhet, att ha tålamod med sig själv är betydelsefullt, men tar tid. En informant påpekar att hon måste leva ett begränsat liv, att pröva nya saker, men i långsam takt, anpassad efter hennes förmåga. En annan informant berättar, ”jag har svårt med närhet och distans, är övergiven och ensam”. Att vara någon i relation till andra, att bli bekräftad och bli en tydlig individ, att garanteras ett evigt liv skulle vara befriande, menar en av informanterna.

Normsystem

Vardagen måste fyllas med något tryggt och glädjefullt menar en av informanterna, att följa sina löften, att inte göra kriminella handlingar, att bli en svensk, bli arbetsför, fungera socialt och vara trevlig är betydelsefullt. En yttre ordning kan ge en inre ordning. Att skapa traditioner, att ställa rimliga krav går inte att uppnå till 100 %. En annan informant berättar: ”Det är svårt att hålla ordning på saker, jag klarar inte av vardagliga kontakter.”

Beskrivning av fotografier på närstående

En av informanterna har fotograferat en man i 40 årsåldern tillsammans med två barn. Fotot är taget i ett rum med färgrika barnteckningar på väggen, vilka föreställer dels en stor svamp med en vacker himmel, dels en väg som bildar en oändlig tunnel. En kvinnlig informant, har fotograferat en man, som ligger på en soffa med bortvänt ansikte. Framför mannen står en chipspåse och på soffkanten finns ett antal prydnadselefanter. Flera av informanterna har fotograferat barn, varav en man, har fotograferat en kvinna i 35-årsåldern med en baby. Övriga barnfotografier har tagits av kvinnliga informanter.

Ett fotografi på närstående föreställer ett en man som sitter på vinden framför en dator, ett annat är taget på en äldre mycket blek man i en sjuksäng. En av de kvinnliga informanterna har låtit fotografera (arrangerat) en äldre dam med en stor bukett blommor i famnen. En manlig informant har fotografera en grupp kvinnor och män i 40-50 årsåldern. Fotografiet är taget i en klassisk hemmiljö, soffor från 1800-talet, kristallkronor, stora antika ljushållare med levande ljus, äkta mattor och gobelänger med olika motiv. Bordet är dukat med en kaffeservis från tidigt 1900-tal.

DISKUSSION

En sammanfattande tolkning av resultaten i delstudierna är att existentiell ensamhet (fig1) bildar ett livsmönster hos personer med psykiska funktionshinder, som troligen utgör ett hindrar för dem att leva ett *fullvärdigt liv*. Informanternas *negativa självbild* utmynnar i en såväl reell som existentiell ensamhet. Ett fullvärdigt liv, enligt de informanter som ingick i studierna innebär att finna *mening med livet*, ha *kontroll* över sitt eget liv och ha ett *socialt utbyte*.

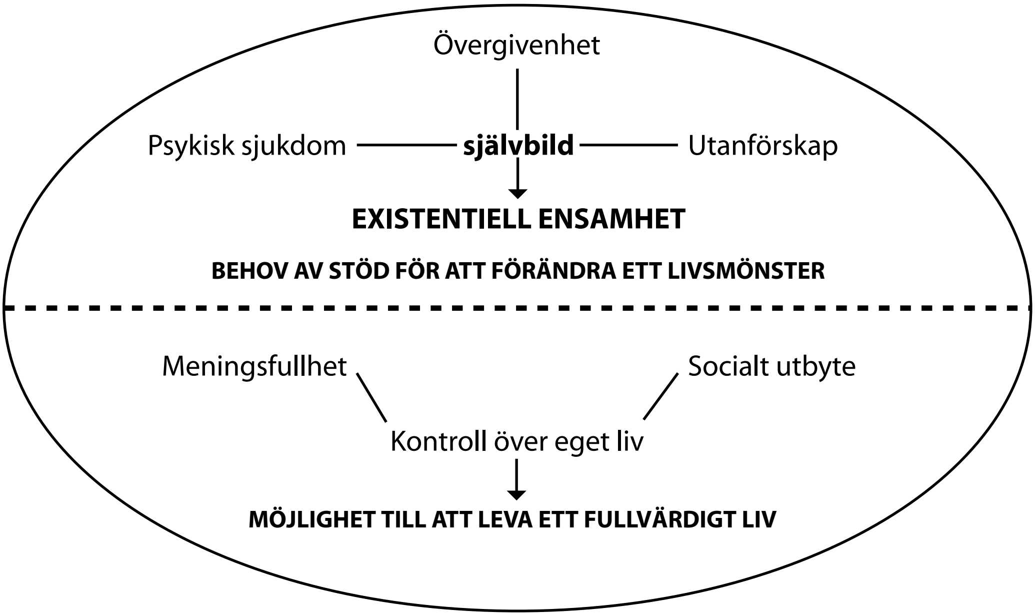

Fig. 1 Existentiell ensamhet hos personer med psykiska funktionshinder

Berättelserna däremot beskriver en självbild hos en människa med ett avvikande beteende i förhållande till andra, samt känslor av *övergivenhet* och *utanförskap*. Denna självbild resulterar i ett specifikt underlägset och osäkert sätt att förhålla sig till omvärlden. Både informanternas berättelser och forskarens observationer gav en bild av informanterna som försiktiga och avvaktande i sin relation med andra människor. Osäkerheten och rädslan för att inte räcka till, samt okunskap om hur man etablerar och behåller en relation blir för informanterna stort och oöverstigligt. De avstår därför från att skapa relationer med människor och ersätter istället denna form av relation med sitt förhållande till föremål, djur och religiösa företeelser.

Informanternas berättelser om sin ensamhet kan tolkas som att ensamhet är en subjektiv känsla som kan vara positiv eller negativ, beroende på vad som händer under livets gång. Innebörden i informanternas beskrivningar om sin ensamhet är outtalad, men kan tolkas som negativ. När informanternas ensamhet blir riktigt påtaglig, hanterar de sin oro på olika sätt. En del blir aktiva och promenerar långa sträckor, andra blir stillasittande och menar att de inte ”bryr sig”, andra föredrar att sova bort tiden. Flera informanter menar att de får hallucinationer om det blir ensamma under längre tider. Arbetsverksamheten och stödinsatser från psykiatri och socialtjänst är av betydelse då dessa hjälper dem att minska ensamheten. Antalet personer som på olika sätt har att bistå informanterna med stödinsatser är stort och kan innebära att en och samma informant kan ha upp till ett femtontal personal till sin hjälp. Alla kommer de med sina goda råd om vad de anser är bäst för informanten och som denne känner att han/hon måste ta hänsyn till. Risken finns för att informanternas befintliga lilla privatliv får ge vika för de professionellas goda råd och åsikter.

Samtliga informanter vill ha vänner, men då på sina egna villkor. De saknar kunskaper om hur de skall gå till väga för att få och behålla en vänskapsrelation. Informanternas vänskapsrelationer synes bygga på en ensidighet, såtillvida att informanterna önskar att vännerna skall finnas till och stå till deras förfogande när de har behov av dem. Det framkommer också att det är viktigt för informanterna att bli uppskattade och uppmärksammade. Således bygger vänskapsrelationer helt och hållet på att den ena parten är aktiv och den andra passiv, relationen kan liknas vid ett ”mor och barn” förhållande. Ytterliggare en reflektion är huruvida informanterna någonsin haft en riktig vänskapsrelation eller om de alltid levt i ett utanförskap. Informanterna skiljer sig åt i sina beskrivningar, någon har berättat att de hade vänner när de var barn, andra menar att de alltid varit ensamma. En annan informant berättar att det är tragiska livserfarenheter som har orsakat att han/hon är ensam.

Enligt Carter (2006) tillhör ensamheten det moderna samhället, storstaden, splittrade familjer. Känslor av ensamhet uppstår när människors livssituationer förändras som när ett barn föds och skiljs från mamman genom att navelsträngen klipps av. Andra stora förändringar i människors liv är då tonåringen för första gången flyttar hemifrån, eller i samband med en skilsmässa eller en persons död.

Nilsson (2004) menar att alla människor försätts i ensamhet någon gång i livet, vi föds ensamma, vandrar genom livet som separata individer och dör ensamma.

Samtliga informanter som ingår i denna avhandling, visar på att deras utsagor också innehåller en existentiell ensamhet som meningslöshet och hopplöshet. Den existentiella ensamheten förknippas vanligtvis med personer som har en psykisk sjukdom som schizofreni. Enligt Fromm – Reichmann (1959) har dessa personer har en social ensamhet. Det är sjukdomen i sig, som enligt informanterna, har medfört en existentiell ensamhet. De beskriver att de upplevde sig övergivna av vänner och närstående när de blev sjuka, de kände sig som udda medborgare, misstänksamma mot andra, grubblade över detaljer. För att skapa sig en inre trygghet söker de efter en tro, samtidigt som de förkastar tron på Gud bland annat pga. sina tidigare erfarenheter och rädsla för att tappa fotfästet igen. Informanternas grubblande över sig själv och sitt egenvärde får en avgörande betydelse för informanternas förhållande till sin egen död och vad som händer därefter. En central fråga för informanterna blir därför hur de i sitt nuvarande liv ska kunna bli en egen individ med egna åsikter, egen tro och att vara någon i relation till andra.

Enligt Kierkegaard (1992); Jeffner (1998); Nilsson (2004) är ensamheten ett mänskligt fenomen, där de flesta lär sig att hantera och acceptera sin ensamhet. De som inte kan hantera sin ensamhet försätts i ett stämningsläge, en existentiell ensamhet, med en ängslan med de vanliga frågorna om livet som; Vad är meningen med livet, Vem är jag, Varför existerar jag?

Nilsson (2004) har studerat ensamheten utifrån ett vårdvetenskapligt perspektiv och menar att existentiell ensamhet vid psykisk sjukdom är upplevelser av ett känslomässigt obehag, själslig smärta, saknad och tomhet. Informanterna i denna avhandling talar om sina existentiella upplevelser och psykiska sjukdom genom att söka en mening med livet och förklaring till varför det är som det är. De lever som i ett vakuum med återkommande frågor om hur de haft det och hur de har det.

Inom religionen är ensamheten en godartad känsla, menar Nilsson (2004), eftersom människan relaterar till Gud och tillsammans med Gud blir en människa inte ensam. Informanterna i denna studie har dåliga erfarenheter av sin relation till Gud, samtidigt som de längtar efter en relation till Gud eller religiösa företeelser som skulle kunna ersätta mänskliga relationer. I stället för mänskliga relationer har många av informanterna relationer med djur. I denna relation känner sig informanterna jämbördiga, vilket innebär att deras upplevelser av mindervärdighet försvinner. Samma värde fyller relationen till föremål. Osäkerheten på sig själv i relation till andra får informanterna att fundera över sig själva, att istället för at relatera till andra människor relatera till djur och föremål samt religiösa företeelser.

Ett förändrat livsmönster

Ett förändrat livsmönster hos informanterna innebär att finna en form av meningsfullhet, kontroll över livet och ett socialt utbyte. Nyman

(2005) talar om människors livsmening. Vardagliga rutiner, arbete och en egen inkomst skulle, enligt informanterna, ge dem möjlighet att återfå hälsan och få makt över sitt liv. Vidare menar de, att maktlöshet enbart har negativa effekter på livsmönstret och att detta inte går att förändra. Att få kontroll över sitt liv innebär för informanterna att bli självständiga, att göra saker och ting åt sig själv och inte alltid för andra, att stå för sina åsikter och att acceptera sig själv och sina brister. Genom att skaffa sig kunskaper om sin sjukdom och dess orsaker, samt bli delaktig i sin behandling skulle ge dem kontroll över sin situation och minska känslan av att vara obetydlig. Särskilda grupper som inriktar sig på att diskutera samhälls- och värderingsfrågor skulle kunna ge en ökad personlig säkerhet samt stöd i det dagliga livet hos personer med psykiska funktionshinder.

Det är viktigt, enligt informanterna, att finna någon sorts mening med livet innan man dör. Om meningen med livet förblir ouppklarat är det svårt att finna en fridfull död. En önskan om ett evigt liv eller tron på ett liv efter döden skulle ge informanterna möjlighet att någon gång bli ”sedd”. De menar, att ett socialt utbyte kan ge livet en mening, men eftersom informanterna saknar kunskaper om hur de skall gå tillväga för att få vänner och dessutom inte orkar intressera sig för någon annan än sig själv, blir det svårt för dem att umgås och etablera kontakter med andra.

Informanterna har behov av och en önskan om att få stöd av vårdpersonal men stödet måste basera sig på informanternas behov, deras utsagor samt i den takt de själva önskar.
Stödinsatserna måste utgå ifrån ett samspel mellan patient och personal. Enligt Brekke och Long (2000) måste personalens stöd bygga på patientens subjektiva upplevelser av sina behov. Informanterna antyder i sina berättelser att personal ofta fattar beslut över deras huvuden. Det är, menar informanterna som om det är personalens liv som ska kopieras och därefter tillämpas av informanterna. Ett genomtänkt och välment stöd som utgår från patientens behov gör att den inre säkerheten ökar. Vidare menar informanterna att personalens attityd till dem har en stor betydelse för deras självbild. En personal i form av en instruktör som har förmåga att ge beröm har större betydelse för utvecklandet av en positiv självbild än många andra insatser enligt informanterna.

METODDISKUSSION

Det övergripande syfte med denna avhandling var att med hjälp av personer med psykiska funktionshinder och deras berättelser om deras syn på det dagliga livet, få en djupare förståelse för deras livssituation och därmed kunskap om vilken form av stöd som de kan behöva för att kunna leva ett fullvärdigt liv.

I samtliga fyra studier har individuella intervjuer med personer med psykiska funktionshinder använts för datainsamling. Vid rekrytering av informanter framkom en omsorg från personalens sida om den presumtiva informanten som innebar vissa svårigheter för forskaren att erhålla informanter. Personalens skyddande hållning mot patienten är naturligtvis viktig samtidigt som personalen i detta sammanhang begränsade patientens självbestämmande. Ur forskningssynpunkt försvårar förhållningssättet att ny kunskap kommer gruppen patienter tillgodo.

I denna avhandling har flera olika datainsamlingsmetoder, triangulering, tillämpats för att ge en bredd och djupare förståelse för livssituationen hos personer med psykiska funktionshinder (Lützén, 1993). Etnografin (Lipson, 1991) förordar flera datainsamlingsmetoder för att fånga såväl process som kunskap. Sandelowski (2000) menar att det finns övertro på intervjuer, varför andra metoder behövs för att belysa det studerade fenomenet.

Förutom intervjuer har även deltagande observationer (**Studie II**) samt fotografier (**Studie III och Studie IV**) använts som komplement till intervjuerna. Datainsamlingen i **Studie I** bestod av djupintervjuer som upprepades tre gånger med en till två veckors mellanrum under ca 1 timme. Att intervjua personer med psykiska funktionshinder innebär alltid krav på forskaren i form av kunskap om dessa personers sjukdom samt förmåga att handskas med de känslor som intervjuerna kan väcka. Intervjuer som datainsamlingsmetod kräver också någon form av relation mellan forskare och informant, som bygger på tillit och förtroende från informanten. Syftet med att intervjua informanterna tre gånger var med ett par veckors intervall var att ge informanterna möjlighet att reflektera över den tidigare intervjun, komma med rättelser eller tillägg men också för öka graden av validitet. Intervjuerna i denna studie har ägt rum i informanternas hem på deras egen begäran. Valet av plats kan i detta fall ha inneburit en trygghet för informanten samtidigt som det kan innebära en ofrihet för forskaren att intervjua någon i dennes hem. Som forskare är det också av vikt att vara observant på utvecklingen av relationen mellan forskare och informant, särskilt då flera intervjuer sker med samma informant och i detta fall personer med psykiska funktionshinder. En intervju innebär krav på en närhet mellan forskare och informant, som från informanten kan utvecklas till en förhoppningar om fortsatt kontakt.

I **Studie II** har deltagande observationer använts som huvudsaklig datainsamlingsmetod. Semistrukturerande intervjuer tillämpades i nära anslutning till observationerna Datainsamlingen ägde rum på en sysselsättningsverksamhet för personer med psykiska funktionshinder. Deltagande observationer är en tidskrävande metod för datainsamling samt innebär dessutom svårigheter att förutsäga datamaterialet kvalitet. För forskaren innebär metoden att hitta en observationsplats där han eller hon har så stor överblick som möjligt över vad som händer och sker i rummet. Samtidigt är det viktigt att forskaren är så ”osynlig” och väcka så lite uppmärksamhet som möjligt. Då platsen för observationerna även var tillgänglig för personer som inte önskade delta i studien var det viktigt att förlägga observationstillfällena till tider då dessa personer inte var närvarande på sysselsättningsverksamheten.

Syftet med observationerna i **Studie II** var att undersöka integrationer och kommunikationer mellan informanterna samt mellan informanter och instruktörer. Problem som kan uppstå i samband med deltagande observationer är flera. Forskarens passiva närvaro i syfte att störa den pågående aktiviteten så lite som möjligt utgör trots alla försiktighetsåtgärder ändå ett störande moment i informanternas dagliga verksamhet. Osäkerhet, misstänksamhet samt ifrågasättande av forskarens närvaro kan uppstå hos de personer som är föremål för observationen, vilket också var fallet i denna studie. Ett annat problem som forskaren hade att hantera var då informanterna sökte kontakt i form av försök att inleda ett samtal. Forskaren försökte att besvara informanternas frågor så knapphändigt som möjligt, utan att bemöta informanterna med en avvisande attityd.

Metod för datainsamling i **Studie III** och **Studie IV** har varit fotografier och intervjuer. Informanterna har tilldelats en engångskamera och ombetts ta bilder på situationer, föremål och individer som är betydelsefulla för dem. Informanterna har i studierna själva berättat om de fotografier de tagit. Detta innebär att datamaterialet i form av fotografier och berättelser i sin helhet utgått från informanterna själva. Denna form av datainsamlingsmetod så kallad själv- fotografering, menar Nolan (2006), är särskilt lämpad för marginaliserade personer. Det var också informanterna som avgjorde i vilken ordning de ville berätta om sina fotografier. Intervjuerna kan beskrivas som ett samtal mellan informant och forskare där informanterna bestämde fokus på samtalet. I samtalet med personer med psykiska funktionshinder kan fotografierna ha inneburit en trygghet och förbindelselänk mellan forskare och informant, vilket underlättat samtalet och berikat datamaterialet.

Denna form av datainsamling kräver att forskaren särskilt reflekterar över sin förförståelse (Sandelowski, 2000; Cronqvist *et al.*, 2004). Forskarens förförståelse baserar sig på mångårig erfarenhet av att arbeta med personer som har psykiska funktionshinder. Förförståelsen har formulerats i text och diskuterats kontinuerligt under forskningsprocessen.

KONKLUSION

Forskning om existentiella frågor hos människor med psykiska funktionshinder är beskrivet i ringa grad. En förklaring till detta är, att det finns en uppfattning om att dessa personers psykiska symtom hindrar dem från att på ett begripligt sätt berätta om sina existentiella tankar och funderingar. Ytterliggare en förklaring kan vara att denna typ av kunskap inte har setts som betydelsefull inom vårdforskning eller att det saknas metoder för att påvisa existentiella tankar och funderingar hos människor med psykiska funktionshinder. Denna avhandling har visat att det är möjligt och värdefullt att tillfråga människor med psykiska funktionshinder om detta. En förutsättning för att lyckas är att personalen är lyhörda för hur existentiella tankar och funderingar uttrycks då detta kan påverka livssituationen. Personalen måste då ha utbildning i och förmåga att samtala om existentiella frågor.

Fotografering som datainsamlingsmetod kan utvecklas som forskningsmetod. I det kliniska vårdarbetet kan metoden tillämpas som ett redskap och hjälpmedel för att förstå patientens livsvärld och därmed förbättra förutsättningarna för att vården planeras utifrån patientens behov.

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SUMMARY IN ENGLISH

Background

The Swedish psychiatric reform of 1995 has resulted in that approximately 43,000 people aged between 30 and 65 are currently living in their own accommodation in the community despite suffering from long-term mental illness. The term mental illness was introduced in connection with the reform, and limits the group to people that as a result of mental illness ”has considerable difficulties in carrying out activities in important fields of life”. The intention of the reform was to present people with mental illness the same rights – but also the same obligations – as people with physical disability, i.e. meaningful daily activities, leisure pursuits and the chances of their own home in the community. Responsibility for care and treatment remains within psychiatric care services while responsibility for daily activities, occupation and accommodation now lies with local authorities.

Key words when the reform was carried out were “normalization” and “integration” in society of the relevant group of people, and these continue to be an important intention in the care of these people. Earlier research shows however that loneliness and social isolation commonly occur among people with mental illness. On the other hand, scant research has been carried out that describes how mentally disabled people experience their own day-to-day life.

Overall aim of dissertation

The overall aim of the dissertation was to gain deeper understanding of the life situation of people with mental illness via their own narratives on how their day-to-day life appears to them, and through this gain knowledge of the type of support needed for them to live a satisfactory life.

The aim of each investigative study was to gain knowledge on how people with mental illness:

- Experience daily life. And to identify potential psychosocial obstacles to attaining meaningful existence. (Investigative study I).

- Express aspects of daily life seen as important (Investigative study II).

- Express in various ways their views on life (Investigative study III).

- Express their fundamental attitude to life (Investigative study IV).

Four investigative studies are included in the dissertation, with qualitative research methods used in all cases. Study participants, or informants, are persons with mental illness, commonly with the diagnosis of schizophrenia living in their own accommodation in the community, and who have continuous contact with both psychiatric care and social service.

Methods

Collection of data for **Study I** involved in-depth interview of two men and two women. Recorded semi-structured interviews were held three times with one-week intervals for each participant. Content analysis was used to identify themes describing aspects of daily life, activities, supportive measures and personal experiences. Data for **Study II** was gathered on work activities, partly via supportive observations of activities and integration, and partly via interviews. The observation proceeds consisted of 23 informants, three instructors and one assistant. Two men and six women took part in the interviews. The aim of the interviews was to acquire a full picture of the daily life of informants. Field notes made in conjunction with the observations, along with taped interviews, were analyzed using hermeneutic interpretation. **Studies III and IV** involved five women and three men from three local authority activity units. These informants collected data in the form of photographs taken that were then used as the points of departure for narratives on their own day-to-day lives. The majority of the informants took approximately 10 pictures each.

Results

Results from **Study I** showed informants were aware both of their illness and their psychosocial limitations, and that they had insight into what they needed to do to influence their situation, while simultaneously having insight into their poor ability to take initiatives. Their narratives reflected their feelings of impotence and inability to take initiatives changing their life situations. The informants expressed feelings of loneliness and longing for close relations, but at the same time avoided personal attempts to establish these by making no active contribution to such relations with other people. Two informants said they had friends, but despite this still felt alone and sometimes experienced difficulties in meeting their friends. All informants expressed the need for professional support but did not want to be controlled.

The informants in **Study II** felt unwelcome, vulnerable and marginalized, and had small hope of a change in their existence, leading to worry about the future. They felt their relations with other people were marked by lack of trust, and thus did not perceive themselves as accepted in the company of other people or society. Some informants occasionally felt like odd and different characters. Their perception of themselves could vary from inadequacy to a sense of uniqueness. Their ambivalent attitudes to being the centre of attention, or not having attention directed at them were also seen in the study. It is suggested that continuity and predictability make it easier for the informants to manage their lives. Their need for predictability also included a longing for own income, own work and the opportunity of creating routines, hoping this would result in greater independence and the chances of planning a future. Several of them felt they had lost previously acquired knowledge and that this was related to their illness and treatment.

Results from **Study III** describe the occupation of informants with themselves and their existence. They relate a sense of spirituality providing them with a feeling of peace and tranquility, but which exists for them only at the start and end of life. The informants felt it important to find a belief, one that could provide them with inner harmony in life. Belief in God was important to them, despite the experience of God having let them down when they needed Him the most. For the informants, life without a belief meant anxiety over what would happen to them and their possessions after death. Their relations to animals meant receiving confirmation, plus the building up of mutual caring that could only be satisfied in living existences. They felt animals were in fact more loyal than people, making no demands, and yet were in a position of dependence on humans. Possessions were of importance to the informants, indicating they view these as part of themselves. To them, giving away a possession entailed giving away part of themselves. Angels were important to several of the informants, since these helped them towards wholeness away from a sense of being broken. Angels knew what was best for them, and could represent a bridge between them and others.

In **Study IV** the informants related how they would like their future to appear. They also related what having an identity meant to them, how an individual's identity is formed, and what having mental illness and feeling good means. They felt a longing for glitter and sparkle, but at the same time did not want to be seen. It was important to think of oneself and not always think of other people, which meant informants found it important to make something of their lives, to find meaning since life could so quickly come to an end. Independence and the building up of inner security were also important. Any changes require time and must be at a pace suited to the informants. One of the informants suggested that if he/she were granted eternal life this would be a relief. The parents of the informants were of importance, particularly mothers. One mother was described as a lifeline when informant entered a worse period. Lack of friends was emphasized. Similarly, several informants expressed the importance of activity centre instructors who they experienced as "keeping them on track", knew what was good for them and gave them praise. Animals were important and seen as affectionate and adaptable. Their homes were important to them; a place where they could be themselves read and watch television. Several of them talked about their computers, with the help of which they were able to contact friends without having to meet them.

Conclusions and significance

Despite efforts for social integration in the community of people with long-term mental illness, the results from the studies above showed:

- The informants felt alone, and were well aware of what was required to change their situations.

Support to informants appeared to be inadequate and misdirected. The informants were aware of what they needed to do to change their situations, but felt that the support they received was inadequate and misdirected.

- The informants felt unwanted, vulnerable and marginalized, with little hope of a change in their life situations. Due to this they felt anxiety with regard to the future.

- The informants experienced three phases in life: birth, empty phase and death. They were occupied in their views of life with not having belief, doubt in God and thoughts revolving around their own deaths and being forgotten once dead. In their narratives they were preoccupied with longing for relationships despite fear of personal closeness.

- The informants had inadequate trust in their fellow human beings and the world, characterizing their fundamental attitudes to life through caution and wariness. Their wish was to be seen as functioning members of the community.

It can be pointed out in summing up that up to the present care of people with long-term mental illness has largely been based on the understanding of professional people as to what is best for patients, and not according to the thoughts and ideas of patients as to what is important to them. Terms such as existential and social alienation do not only serve to display feelings of marginalization among informants, but also shed light on the lack of consistency in what appears to be the prevailing negative attitudes in society towards mental illness. The narratives of the informants show they lack people with whom to discuss their existential thoughts. The studies display how important it is for care personnel to realize that change must be given time and needs to take place on the conditions of mentally disabled people themselves.

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Psychosocial disadvantages in the lives of persons with long-term mental illness living in a Swedish community

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Psychosocial disadvantages in the lives of persons with long-term mental illness living in a Swedish community

The aim of this study was to gain in-depth knowledge of how persons with long-term mental illness experience their everyday situation, in order to identify potential psychosocial obstacles to a meaningful existence. The focus was on psychosocial aspects, such as contact with others and the quality of these contacts. An ethnographic design was used, in order to provide an inside perspective. Four persons with long-term mental illness participated in the study. Three open-ended interviews, at 1-week intervals, were conducted with each informant. Analysis of transcribed material consisted of naive reading and content analysis guided by the investigators' understanding of the psychiatric context. Three themes were generated: feeling lonely but being unable to establish friendships; knowledge of what to do but lacking initiative; and awareness of the need for support but not wanting to be subject to control. These themes reflect contradictions between thoughts, feelings and actions, which seem to contribute to a psychosocial disadvantage in the life of persons with long-term mental illness.

Keywords: ethnographic study, loneliness, long-term mental illness, meaningful existence, psychosocial disadvantages

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Introduction

Approximately 40 000 people in Sweden between the ages of 30 and 65 years are known to suffer from long-term mental illness (National Board of Health & Welfare 1999). Thus, the transition from hospital to community care for persons with long-term mental illness is a growing concern. A specific example is the increase in the number of homeless men and women with long-term mental illness, indicating problems associated with adjusting to a life outside of an institutional setting (Nordentoft 1994).

In Sweden today, the term used to categorize persons with long-term mental illness is mental dysfunction (National Board of Health & Welfare 1999); recognizing that the term 'mental dysfunction' may not be common in many countries, the term 'long-term mental illness' will be used interchangeably in this paper. The change in terms can be interpreted as a change in focus, from illness to (dys)function, but also as an attempt to provide appropriate services that will allow these individuals to live a life that is meaningful and satisfying. People with long-term mental illness are believed to have difficulties in carrying out everyday activities and establishing satisfactory interpersonal relations and, as a consequence, suffer from social isolation (Cullberg 1999, Brusén & Hydén 2000).

People with long-term mental illness living in their own home in the community not only face the challenge of daily physical and social needs, but also that of filling their day with meaningful activities. In a follow-up of daily activities of 498 people within this category, Steinholtz-Ekecrantz (1997) report that 31% of the respondents in their study had planned daily activities, while 69% did not have planned daily activities. However, only 14% wished to have special planned daily activities. A possible explanation could be that some of them had lived in community care settings with regular daily activities. Persons who previously lived in institutions with few demands may not experience the need for activities.

Another factor that may make the transition from hospital to community care difficult is that attitudes towards mental illness have not really changed (Grunewald 1997), meaning that people showing symptoms of psychotic behaviour, such as hallucinations, are not readily accepted by their new neighbours (Palmblad 1992). A question that can be raised is whether there is a tendency to underestimate the complexity of individual needs (National Board of Health & Welfare 1999). Society may also view persons with mental illness as unemployable and unable to function socially. Moreover, there may be a tendency for society to perceive persons with mental illness as a homogeneous group in spite of individual differences.

It is generally assumed that positive reactions from others and a high quality of professional and social support are major factors in creating a meaningful existence for these people (Grunewald 1997). However, to our knowledge there are no studies in Sweden describing how daily life is experienced from their perspective. One exception is a study by Nyström (1999), who interviewed seven people with severe mental illness in Sweden. The findings showed that existential loneliness due to problems in interpersonal relations, lack of interest and inability to deal with frustration was a central problem in the lives of these people. Consequently, severely mentally ill people may not benefit from new experiences in a productive way. Therefore, there is good reason to believe that it is difficult for the severely mentally ill person to bring about the necessary changes for making personal development possible. The findings of Nyström's study, as well as the present organization of psychiatric care and clinical experience in Sweden, indicate the need to further explore psychosocial aspects from the perspective of persons with mental illness residing in the community. Thus, the aim of this study is to gain in-depth knowledge of how persons with long-term mental illness experience their everyday situation in the community in order to identify potential psychosocial obstacles to a meaningful existence.

Methods

Study design

An ethnographic, inductive design (Leininger 1985) was chosen, in order to gain an inside perspective of how persons with long-term mental illness view their own lives. Studies with an ethnographic approach collect data in order to discover common features in how people in a specific culture see and experience their life situation. However, research involving vulnerable people, such as those with long-term mental illness, may be a complex issue (Lützén 1996). Besides the ethical aspects, mistrust and psychotic symptoms may pose problems when conducting interviews. Persons with long-term mental illness, such as schizophrenia, often have many years of experience of psychiatric care, when they have encountered different categories of personnel who have asked them about their psychiatric condition, with the aim of assessing whether their thoughts and notions are realistic or imaginary. Communication often consists of short answers of what they think is expected of them. Medication also has a subduing effect, slowing down thought processes.

Data collection and informants

Selection of informants was purposive in that those recruited were people between the ages of 30 and 63 years, with a long-term mental illness, living in the community with contacts with both psychiatric care and the social services. Their long-term mental illness had caused social impairment or loss of capacity to the extent that it had a direct effect on their everyday lives. The principal investigator (AE) described the study to personnel who, due to having direct contact with these patients, assisted in recruiting people who met the criteria and who were willing to participate. Those agreeing to take part in the study gave their written consent to being contacted by telephone by the principal investigator.

Two men and two women participated in the study. They were interviewed on three occasions, at weekly intervals, each interview lasting approximately 1 hour. The purpose of conducting three interviews was to establish consistency in the data. The timetable of interviews also gave informants time to reflect on the previous interview and change or add to the topics covered. Before the first interview, the significance of informed consent was explained to the informants. They were also assured of confidentiality regarding individual identity. All of the informants agreed to the interviews being audio-taped. In the initial interview, each informant was asked to describe what his or her usual day was like. An interview guide was also used in the initial interview, with questions relating to living arrangements, support, services and daily activities. Interviews were based on Kvale's (1996) self-correcting interview. This technique can be compared with a care dialogue, where informants are asked to describe their daily life, leading to the discovery of new meaning in their experiences as they relate them. The interviewer condensed and interpreted the informant's descriptions and then presented her interpretation to the informant, giving him/her the opportunity of confirming or refuting the stated interpretation.

The names of the four informants in this study are fictional. In order to further protect the informants' identities, it was necessary to change some details in a way that would not misconstrue the data. These details were identified and changed after the analysis and are not considered to be of significant importance in the process of analysing data.

All four informants, Allan, Esther, George and Jenny, were, at the time of the study, in receipt of a disability pension. All of the informants were involved in daily activities at specially allocated day-care centres. All four had had regular contact with a community psychiatric clinic over a longer period of time and were on neuroleptic medication. The women were living in apartments with two rooms and a kitchen, while the men lived in one-room apartments. Three had domestic support from social welfare in the form of cleaning, going for walks and shopping. All the informants met their psychiatrist once a year. Two of them received psychotherapeutic treatment. All of the informants spontaneously confirmed a diagnosis of schizophrenia, and two said that they also had 'physical problems' requiring medical treatment. The duration of the informants' illness was between 10 and 22 years and the onset of the illness had occurred between the ages of 22 and 37 years. The two men were without sexual or marital experience, while the two women were divorced with grown-up children. All had brothers or sisters, but only one had both parents still living. The study was approved by the ethics committee at the Karolinska Hospital, Stockholm (No. 99–019).

Data analysis

All 12 interviews were transcribed immediately after each meeting. The transcribed texts were examined using content analysis to identify topics describing aspects of everyday life, activities, support received and personal experiences (Denzin & Lincoln 1998).

The following steps were taken in the analysis of the transcribed material:

Narrative data pertaining to each informant were read several times, in order to obtain an impression of the whole content of each interview, as well as an overall feeling for the total material.

Categories were then compared in order to reduce data into themes. The suggestions for themes were discussed and compared by all of the investigators in order to reach validity in this study (Baxter 1991). Through this internal validation process, the researchers developed a deeper understanding of the psychosocial disadvantages in the lives of persons with long-term mental illness living in a Swedish community. An example of the analysis is shown in Table 1.

Findings

Three themes that illuminate psychosocial aspects of daily life were constructed: feeling lonely but being unable to establish friendships; knowledge of what to do but lacking initiative; and awareness of the need for support but not wanting to be subject to control. On the one hand, the informants' experiences reflect aspects of social isolation of anyone who lives alone without close relationships. On the other hand, as this study reveals, persons with long-term mental illness may know or have insight into the causes of their social isolation but for some reason are unable to act upon that knowledge. All the informants said, for example, that 'having friends' and being 'occupied' are essential. They all said that they were aware of what is needed to 'feel better'. However, they were unable to act on this insight. All of the informants reported having voice hallucinations when they failed to alleviate their loneliness, claiming social contacts to be essential. However, the informants' ability to act on this insight varied, with one person feeling unable to achieve anything at all that could be seen as positive, while others regarded their efforts as more or less successful. Hence, the meaning of their experiences can be described in terms of dialectical relationships, as illuminated by the themes, which can be described in the following ways.

Table 1
An example of the steps of the analysis, showing statement, meaning unit and theme separated by '/', all belonging to the first theme: feeling lonely but unable to establish friendship

Statement	Meaning unit	Theme
I wish that someone would come and visit me as 'Jenny', and not as someone who is mentally ill. / Often I can't face meeting my friends.They just talk about their illnesses	Loneliness	Feeling lonely but establish friendship

Feeling lonely but being unable to establish friendships

This theme reflects the poverty pertaining to the area of social relationships. Although the informants, who lived alone, said that they longed for close relationships, they indirectly avoided forming close relationships by not actively finding out how to be a friend or what friendship feels like. Their long or intermittent periods of hospitalization had placed them outside the social arena. Two of the informants said that they had friends but still felt lonely and sometimes experienced difficulty in meeting their friends. Even if the informants had routines, such as daily occupations or shopping, they felt a vast emptiness and loneliness. The people they met were not persons with whom they could form a close relationship. However, the professionals who came to their home or whom they met at the clinic eased the loneliness they felt. One informant was particularly satisfied with her 'contact person', who was always accessible and provided praise and encouragement. This enabled her to face new situations, thus giving her a sense of development. The other interviewees were, however, not too happy with their professional contacts:

> It's mostly the cleaners that come here. (Allan)
>
> At least admission to hospital means the chance of meeting other people. (George)

The informants were also dissatisfied with their private interpersonal relations. Ruminating about the past, before they became ill, reveals the need for friends to ease their loneliness:

> Nobody wants to meet mentally ill people. Nobody comes here to visit. There's just one man whom I've been seeing for 15 or 16 years and who is also lonely. My loneliness came when I got ill. Before that I had lots of friends. It was like they didn't want to know me once I got mentally ill. When I'm really alone I start brooding about a speck of dust that can grow to the size of a mountain. In other words, I go mad. (Ester)
>
> I had friends then [when I was nine years old] – that was the best time of my life. (Allan)
>
> I long for a female partner . . . meeting a woman is my greatest wish. I'm sure I'd get well then too. (George)

Knowledge of what to do but lacking initiative

This theme refers to informants being aware of their psychosocial limitations and having insight into what they need to do in order to improve their situation, but at the same time having insight into their lack of initiative. All the informants were aware of the problems associated with mental disability and spoke freely about that. However, their stories reflected how, at times, they felt powerless and unable to take the initiative to bring about changes in their lives. All the informants stated, for example, that having a job was essential to maintain health. However, their ability to obtain work varied:

> I don't know if I'm capable of starting work, but I need to get out and meet other people. It's a bit nerve wracking. I'll have to get dressed and ready the night before and lie on the bed. Ideas fill my mind and I imagine everything being like this and like that. (Jenny)

How the informants perceived what 'they should do', i.e. the social norms, contrasted with their own experience. Allan, for example, 'knows' that it is not meaningful to worry about the past and that he 'should' go to work and refrain from eating constantly. He said that his presence at work had been sporadic, because he is lazy and has to force himself to go to work. Once you've been ill you have to come to terms with yourself, he said:

> It's depressing not being able to work in a sheltered workshop, but it's impossible for me when I can't even get up in the morning and fix a lunch box. In fact, I've lain down thinking it through for years now. I long to return to when I was a kid but I know that's not possible. No stimulation from work, fed up with the place, they've changed it and there are no skilled workers there anymore. It's more about therapy and talking than woodwork. (Allan)

George also 'knows' that he has difficulties when in a new environment or with strangers. On the days he finds nothing meaningful to do, he does nothing the whole day:

> I don't trust myself, can't see clearly, short-sighted, I've got no real identity. I was given no space as a child. I've done mad things in my life, and when I'm at the pub or whatever, memories sometimes come back and make me feel so ashamed I have to go home. (George)

All four informants knew that their hallucinations placed restrictions on their lives, especially in contact with others. Similarly, Jenny knows that the 'voices' come to her when she is alone and thus thinks that she ought to get a job. However, she does not know how she could achieve this because she is too old, believing that nobody wants to employ someone who hears voices:

> I've lost my grip, but I'm starting to get it back again and I avoid the hospital. I need routines, and not least someone who says stop. When you've lived alone, hearing the views of somebody else about things can be very useful. (Jenny)

Awareness of need for support but not wanting to be subject to control

This theme illuminates the informants' awareness of the need for support in order to carry out typical daily activities. Their descriptions of the healthcare professionals they met in their daily lives revealed that up to 15 professionals were involved in the planning of their care and treatment. The informants considered that this support was of vital importance. George says that he is pleased with the training programme arranged for him by professional caregivers:

> The staff have helped me to cut down on my fantasies . . . maybe I will feel more secure when I sense they're behind me. (George)

Esther also indicated that she is satisfied with the support provided by the psychiatric care workers:

> My contact person gives me encouragement and praise; he says he is proud of how I'm doing. (Ester)

Discussions among the psychiatric professionals about whether the patients should have psychotherapy, what medication they should have and what they should do to create a meaningful life were, however, often conducted without the informants' participation. This non-involvement could be connected to the informants' lack of initiative, which is observable, as well as to the tendency of others to take charge. In Allan's case, for example, it was his brother who initiated psychotherapy, arranged for two people to come and clean his apartment, and decided that walks were good for him. The reason why two people came and cleaned was that the community decided, without conferring with Allan, that his house was 'too messy'. The consequences were that Allan paid this double cost. He said 'At least someone comes and visits'. Hence, to get the support they needed, the informants also had to accept a higher degree of control than they wished for. Jenny also expressed how she felt when the professionals 'took over' but, at the same time, she acknowledged that she needed their help:

> They work hard to make sure I don't sit inside smoking. They've talked about sheltered housing and a guardian. They say I've got to do what they say otherwise there will be trouble. I can manage by myself. Sheltered housing is not for me; they go on and on and take control. But I do need help otherwise I would spend too much time in bed. (Jenny)

Discussion

The research interest of the present study was to gain in-depth knowledge of how persons with long-term mental illness experience their everyday situation in the community in order to identify potential psychosocial obstacles to a meaningful existence. Data were collected by interviews. Three themes were generated from the content analysis: feeling lonely but being unable to establish friendships; knowledge of what to do but lacking initiative; and awareness of the need for support but not wanting to be subject to control.

The interviewer's experience of caring for individuals with long-term mental illness was highly advantageous in the interviews. Although the informants had concentration difficulties, repeated interviews yielded meaningful data. Interview length was adapted to suit each individual. Moreover, the repeated interviews gave the participants time to reflect on the previous interview and to change or add to topics covered. There were elements of longer periods of silence or discussion of general matters in all of the interviews, which is not unusual because the research issue itself was of a general nature. Participants had the opportunity of choosing the interview location, which can contribute to their sense of autonomy and thus make them more likely to share thoughts and feelings. Anthony *et al.* (1994) point out that persons with long-term mental illness 'function' better in environments in which they are at ease. However, there may be a possibility that the staff selected individuals whom they thought would be appropriate. Regardless of the selection of informants, the experiences that unfolded generated interesting and relevant findings. Ricoeur (1988) suggests that when people describe their day-to-day experiences, their descriptions shift between the present, past and future. When the informants were asked to describe their day-to-day situation, we can presume that they related to how things had been and their views on the future.

All of the informants were aware that their diagnosis was schizophrenia. According to Flyckt *et al.* (1999), many persons with schizophrenia seem to be unaware of their diagnosis. Although our study was small, the informants were aware of their diagnosis and revealed much insight into their daily lives, their psychosocial needs and personal limitations. Awareness and insight are fundamental concepts within psychotherapy. This study shows that people with long-term mental illness cannot change their situation even if they are aware of their needs. Other studies support this conclusion. Topor *et al.* (1998) argue, for example, that long-term mentally ill persons are not helpless victims but are well aware of their difficulties and that not to act could be a conscious strategy to avoid something worse.

The central features of the material gathered are the informants' descriptions of existential loneliness, that is, feeling alone even with other people, being aware of what is needed but unable to realize wishes or needs, as well as not taking part in care planning. These can also be identified as previously known psychosocial disadvantages in establishing a meaningful life. West *et al.* (1986) consider loneliness to be the most common phenomenon found in people with schizophrenia. In his study of people with schizophrenia, De Niro (1995) showed that they are frequently alienated, that is they often distance or separate themselves from their surroundings, live in isolation and experience difficulties in feeling a community spirit. Harding *et al.* (1987) maintain that mentally dysfunctional people find forward thinking difficult. The informants in this study conveyed passivity in that they wished others to come to them and show an interest in them. Taking the initiative to visit others was a less obvious step. One question that requires further research is whether failure to direct interest towards others is a specific dysfunction or a protection against rebuff. Once a person has been rebuffed, something the informants had been exposed to on several occasions, they would not take a new initiative, and seemed to avoid the risk of a further rebuff. Behind the statements about relationships, however, we can discern a feeling of a deeper need; to meet with someone who can help them to make the changes in life that they desire but that are so difficult to carry out. Borge *et al.* (1999) point out that long-term mentally ill people may perhaps adapt to being alone. This study shows that none of the informants wished to be alone, but rather had difficulty in taking steps to meet others. This left them waiting, longing and fantasizing about how a relationship could be.

The second theme, knowledge of what to do but lack of initiative, is concerned with the informant's awareness of what they need in order to improve their situation. However, the step from awareness to action is big. The lack of initiative seems to be connected to the meaning the particular activity has for the individual person. If, for example, the informant thought that the daily activity would lead to new contacts, he or she would take the initiative. However, to these individuals, activities often have no personal or material meaning. Neither can it be assumed that they find meaning in activities organized by others. They also suffer from ambivalence and feel anxiety in situations where they have to take decisions. According to Hydén (1995) and Gråwe & Lovaas (1994), work takes on a meaning if a person feels needed by coworkers who rely on his/her participation. Henriksen & Vetlesen (1997) similarly point out that unemployment does not only have financial effects but also influences a person's self-image. In the case of this study, the informants presented themselves as 'lazy' and 'worthless'. Work had a value because others appreciated it. By working it is also possible to establish contacts with people other than the professional caregivers.

The informants' psychosocial disadvantages are supported by other studies as well. Borge *et al.* (1999) suggest that professional contacts are the main contacts for long-term mentally ill people and that these contacts are stronger than those with friends and acquaintances. According to Pattison *et al.* (1975), people with schizophrenia have four to five people in their network compared with the average of 20 to 30 relationships of the normal population. As mentioned earlier, the patients in this study knew what should be done, but did not know how to accomplish it. The professionals may not be aware of the nature of the patient's problem or else deem the problem to be of little or no significance. In the present study, one informant was particularly satisfied with her contact person, who was always accessible and provided praise and encouragement, enabling her to face new situations and feel a sense of development. Yoder & Rode (1990) confirm the importance of a personal care provider for schizophrenic patients, who find it a positive experience to be supported by a carer who is critical in a positive way, gives them attention, and comments on their progress and resources. In their study, Brekke & Long (2000) concluded that it was necessary for all psychosocial rehabilitation focusing on functional and clinical changes to be based on subjective experiences. If the individual's experiences are disregarded, then neither clinical nor rehabilitative efforts will have any effect.

Conclusions

This study shows that the informants diagnosed with schizophrenia had insight not only into their illness but also into their psychosocial needs. However, in spite of many professional contacts, these needs are not satisfied. Lack of friends and meaningful activity, and lack of participation in their own care, can leave an existential vacuum. A common feature is that all the informants were aware of what was required to change their situation but the support they received seemed to be inadequate or misdirected. The study has increased our understanding of how the inconsistency between being aware of essential needs and not knowing how to satisfy them places persons with long-term mental illness at a psychosocial disadvantage. As lack of insight does not seem to be the only obstacle preventing long-term mentally ill persons from making friends, working and managing daily life without support from professionals, further research concerning these obstacles is needed. Rehabilitation for the long-term mentally ill has so far been based mainly on the perceptions of professional care providers, who decide what they consider to be is suitable for the patient, and not on the patient's own thoughts and ideas of what is important.

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Social and existential alienation experienced by people with long-term mental illness

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Social and existential alienation experienced by people with long-term mental illness

The aim of this study was to explore how people suffering from long-term mental illness and who live in the community experience their daily lives. The study was based on an ethnographic framework involving participant observations with 23 individuals from two rehabilitation centres and interviews with six women and two men. The observational notes and interviews were recorded, transcribed into the data and analysed based on the phases of hermeneutic interpretation. The process consisted of identifying tentative interpretations that highlighted various impediments that prevent people with long-term mental illness from having an active life. The impediments can also be interpreted as a form of alienation, an interpersonal phenomenon and a consequence due to of the lack of social acceptance towards mental illness. The participants expressed concern about the future and lack of hope. Viewing themselves as being 'odd' is not a symptom of mental illness, but rather evidence of experiencing existential and social alienation not only as a consequence of other people's reactions but also their own negative attitudes towards mental illness and effects of their cognitive dysfunction.

Keywords: alienation, ethnography, hermeneutic interpretation, mental illness.

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Background

The number of people suffering from long-term mental illness[1] whilst living in the community (as a result of psychiatric reform) has increased in Sweden as well as in many other countries. Although the reason for shifting the responsibility of care from psychiatric facilities to the community can be justified, the key social consequence is that mental illness has now become more 'visible' to general society. When people who suffered from the different types of mental illness were 'protected' and cared for in long-term psychiatric facilities, the concept 'out of sight out of mind' existed.

Currently, the social distance between the mentally ill and the general community has decreased as an important consequence of organizational change. In order to obtain a positive self-image and ability to achieve social rehabilitation, it is important from the perspective of the mentally ill that they are accepted by the people they meet in their daily lives whilst living in society.

Whether or not the increased 'visibility' has changed the attitude towards people with mental illness in a positive sense is uncertain. Individuals with psychotic behaviour such as hallucinations and other socially eccentric behaviour have proved to frighten some people within the community (1). The mindset towards mental illness tends to be negative and value laden. For example, people with mental illness are commonly generalized as a group and described as people who have 'character deficits' such as potential violent behaviour, laziness or weakness (2).

The most significant consequence of negative attitudes towards mental illness is that sufferers become an alienated population (2), which makes social rehabilitation of the mentally ill problematic. In a more recent study, Bengtsson-Tops (3) found that individuals with mental illness are sensitive to other peoples' negative reactions and that these can add to an increased tendency to develop poor self-image and feeling of despondency.

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[1] In this paper, long-term mental illness includes all types of mental illness that results in dysfunctions in daily life that require long-term treatment and care.

The intention of the psychiatric reform in Sweden (and elsewhere) was to provide people suffering from long-term mental illness with meaningful daily activities, leisure opportunities and ability to live in their own flat (National Board of Health Welfare, 4). Individuals, who have been relocated into the community with the support of a mental health team, are expected to work and live amongst others based on the principle of equality (4). The extent and type of community support provided to sufferers and their families is usually determined based on an assessment of their ability to care for themselves and the availability of family support. This usually includes an appraisal of the individual's demonstrated and predicted ability to perform common daily activities as well as determining the person's compliance to treatment.

Ivarson's study (5) demonstrates that individuals with mental illness have difficulty in remembering instructions and organizing and structuring activities within therapy. This finding is similar to the study by Weickert *et al.* (6) who found that people with schizophrenia have a cognitive impairment. This means that they have a low attention span and thus have difficulty in recalling verbal instructions in order to carry out daily activities.

Therefore, the needs of the mentally ill are complex. Some people need help with basic self-care activities such as hygiene on a daily basis whilst others are more self-sufficient and able to work in a sheltered environment (7–9). However, the majority of the results from these studies are based on objective observations and evaluations. The question is how do people with mental illness view their own lives? Erdner et al. (9) suggest that people with a long-term mental illness express an understanding of what they need in order to have a better quality of life, but lack initiative to make the necessary changes in their lives.

The participants, who were observed and interviewed for the purpose of this study, expressed a sense of loneliness and missed having a 'family' as positive aspects they desired in their lives. However, despite this insight, they did not make any attempts to establish friendships or meaningful social contacts. The participants were also aware of their need for support, but did not want to be 'controlled' by others.

Aim of study

A review of the literature reveals that there are few studies that provide evidence that the shift from institutional to community care has substantially improved the quality of life for people with mental illness (as experienced by themselves). Fear of social rejection, the feeling of alienation and social discrimination cannot be viewed as symptoms of an underlying pathology (10), but as a subjective experience of individuals whose lives are in the hands of others. As a result, the aim of this study was to explore how people with mental illness experience their daily lives and to reveal aspects of the every day world that these people experience and consider to be important.

Design

The methodological design of the research builds on the main tenets of ethnography. In that, an *emic* perspective is considered important when gathering data concerning the views and experiences of others (11). Ethnographic methods commonly begin with an inductive approach with the goal to gain an understanding of the social world of the participants from their own perspective (12). Within this study, the approach for the main researcher was to spend time with a number of mentally ill people on a daily basis, creating an opportunity for participant observation and interviews as key sources of data. The concept of alienation used in the part of the hermeneutic interpretation of data, focusing on the social and existential aspects. Generally, the concept of alienation is defined as an estranged relationship between individuals (or groups) and their social environment. Social alienation raises questions concerning persons with mental illness ability to live an active social life. Existential alienation places a focus on worldview as expressed by these persons. A worldview encompasses for example, values, a sense of meaning and outlook on the future.

Confidentiality was assured to all participants who provided information for this study.

The ethics committee at the Karolinska University Hospital, Sweden (No 55/02) approved the study.

Data

The research was conducted at two different rehabilitation centres located within a Swedish city, provided for people with long-term mental illness. The rehabilitation programmes endeavour to increase the participant's independence, develop routines and ability to 'normalize'. The 'job' which was included in the rehabilitation programme was arranged in the same way as the open labour market, but the participants did not receive a salary for their work.

Both the observations and interviews were carried out at the largest of the two rehabilitation centres, whilst only interviews with the smaller centre. Participants were purposely selected, in that those recruited were individuals between the ages of 21 and 57 years, suffering from a long-term mental illness, living in the community and training for work. The researcher (AE) outlined the study for an instructor, at the rehabilitation centre, who assisted with implementing the data collection.

Six women and two men were interviewed. The interviews lasted from a half to one and a half hours each. The interviews were based on the principles of an open life world approach (13). The goal was thus to encourage the participants to reflect on their role and perspective on daily life as openly as possible. All interviews except one were audio taped and later transcribed verbatim. The collection of data also included participant observations with 20 women and three men focusing on both individual and interpersonal activities. The observations resulted in the development of field notes regarding activity, work and informal dialogs with participants over a period of 16 days.

All of the participants in this study received a disability pension or social allowance because of long-term mental illness. Approximately, half of the participants had regular medical assistance and all of them saw a psychiatrist, at least once a year. They all had a basic school education.

Analysis

Firstly, the transcribed interviews and field notes were read, providing an overall picture for the researcher. The first analytical phase involved identifying similarities and differences within the explicit remarks from participants concerning the various impediments on an active life. Similarities were then subsumed into themes. Different manifestations within each theme formed the sub-themes.

The second phase of analysis involved identifying more or less hidden the meanings in the collected data. Preliminary findings, which revealed underlying meanings, were reallocated into six tentative interpretations. Validity in the tentative interpretations was estimated based on the following criteria of validity (13).

1 No contradictions in data concerning the tentative interpretations were found.

2 Each interpretation highlighted the actual segment of data.

3 The connection between the external and the internal world, i.e. as experienced by the individual, was also emphasized. The basic idea was that an explication of a phenomenon in the external world also clarifies the internal world.

4 The level of abstraction was connected with the principle of going from parts to the whole and *vice versa*. It was important to obtain consistency in the mesh of tentative interpretations. In this process, an interpretation on a higher degree of abstraction was possible.

5 The consistency of the interpretations was affirmed when the researchers agreed that no significant part was left out in the comprehensive understanding that completed the analysis.

Findings

Phase 1

Contents of meaning in data. In the first phase of analysis, overt contents of meaning in interviews and field notes were structured into themes and introduced in the findings in Table 1 (interviews) and Table 2 (participant observation).

Phase 2

Interpretations. The second phase of analysis, the underlying meaning within the interviews and field notes, proposed six tentative interpretations. These highlighted partly hidden impediments for an active life.

Tentative interpretations. It is an impediment for an active life if you:

- barely know who you are in relation to other people;
- cannot anticipate anything in the future;
- have a lack of knowledge and poor learning capability;
- have earlier memories and experiences of life that predominately consist of difficulties;
- worry about reasons for being mentally ill;
- find it difficult to develop an interest in other people.

You barely know who you are in relation to other people. A number of the participants in this study expressed a lack of confidence in them in relation to other people. They did not experience themselves as accepted participants in a companionship or social existence. When they participated in an activity, they felt like it was not on the same terms as for other people:

> 'I feel like an odd person when I am with other people. I have the ability to make contact and don't want to be a recluse. It feels like I don't fit in'.

Taking on the position as an outsider sometimes appeared to be a conscious action. Some of the participants spoke in fact of themselves as odd and different. They compared themselves with others and found that they were sometimes inadequate, but also that they were uniquely odd'. The comparison could thus result in contradictory attitudes. The participants experienced on one hand that they were inadequate, but on the other hand that they were unique human beings. Some of them even expressed a feeling of contempt when talking about people who seemed to be 'lost in a crowd' and who attempted to make an impression of wanting to be like everyone else.

However, the participants made numerous efforts to get attention from the instructors, presumably because they found it very hard to be appreciated by other participants in the rehabilitation programme. This was indicated in the following field notes:

> 'The participants attempt to strike up a conversation with the instructors by just talking about radio programmes and newspaper articles'.

Thus, a degree of ambivalence seems to exist in the attitudes of the participants, on one hand they want to be the centre of attention and on the other, they do not want attention directed at them. An impediment for living an active life seems thus to be that mentally ill people are confused about who they are in relation to others.

Table 1 Contents of meaning in interview statements

Themes	*Sub-themes*	*Examples*
Feelings which seem to preserve the situation	Meaninglessness Restlessness. Satisfaction with the situation Feelings of insufficiency when being brought face to face with an active lifestyle. Lack of confidence in one's own capability for changes.	I feel empty, everything is difficult. I can't stay at the same place. Glad to have my own flat. I feel locked in. Can't manage to go out by myself. I panic when I go to a party. It is awful to be at the same place for so many years, but I can't do anything else.
Obstacles for planning future life.	It is difficult to create routine. It is hard to be accepted in society. It is difficult to anticipate problems and how to meet them.	You simply have to live for the day. It is hard to maintain one's rights and to be heard. I am afraid to face the day when they say that I can't stay at the rehab centre any longer.
Problems with knowledge and learning	To forget previous knowledge Wanting to know more Not being sure about what you want. Not knowing the reason for being mentally ill.	My memory is bad. I can't learn anything new. I want to study very slowly. I don't know if I want to learn anything new. Examining how my parents have been could provide answers and increase the knowledge about my own disease.
Unsatisfying interpersonal relationships	To feel like a stranger when together with other people. It is trying to be with other people.	I feel like an odd person when I 'm with other people. I have always found it difficult to socialize with others. Maybe I don't want to drag them into my world.
Participants own experiences of obstacles for changes	Lack of intentions. Too much anxiety. Not feeling wanted. Not being interested in others. Several life tragedies appear at the same time. Not being able to anticipate anything.	I think that I should participate, but I don't really want to. Anxiety makes it impossible to work. I can't force myself. It doesn't matter what I do. I don't fit in. It is not only me that doesn't take interest in others. My divorce coincided with my parents' death and a car accident and then I started to hallucinate. I am deeply concerned about the future and I don't think I will manage to keep a job.

You cannot anticipate anything in the future. Continuity and predictability probably makes it easier for the participants to manage their social life. Their need for predictability also included a yearning for own income, employment and ability to create routine. Some of them expressed that this would result in an increased independence. The ability to plan one's future also appears to be an important way to gain control over oneself and life:

> 'It's important to have your own income. I want to be able to take care of myself'.

However, the feeling of always failing is probably reinforced when the overall goals are set relatively high. For example, the goal to achieve one's own income can be so high that it directly carries expectation of failure. Furthermore, the participants in this study seemed to be frightened to plan anything that could lead to failure. They

Table 2 Contents of meaning in field notes from participant observations

Theme	*Sub-theme*	*Examples*
Support from professionals is important	Participants' attention is directed to instructors. Approval from instructors is highly appreciated by the participants. Instructors' attention is more appreciated than attention from other participants.	The participants often ask instructors for help. Instructors try to break passivity. Credit from instructors makes the participants more active. Efforts to make contacts are directed towards instructors, not towards other participants in the programme.
It is difficult to initiate social contact without help from instructors.	The participants find it hard to communicate with other participants. Presence from instructors facilitates conversation.	Participants try to get in contact with each other but they don't know what to say. Those who want to talk are seated next to instructors during coffee- breaks; those who are sitting with other participants are silent.
Previous negative experiences influence creativity in an inadequate way.	The participants hesitate to make plans because they can not anticipate their mental condition. Memories from interpersonal relationships that went wrong make participants extremely cautious.	Some participants want to plan leisure activities, but they fail to do so because of the risk that they wouldn't feel well. Participants talk about earlier frustrations as a reason for not making an effort to escape loneliness.

expressed a sense of hopelessness of not being able to influence the situation. As a result, they did not change anything at all.

> 'I don't have any thoughts about desires, I don't care. I feel like I can't make a decision, the days are just like they are'.

Therefore, the need for total predictability can lead to negative expectations. One who expects failure avoids being disappointed when failure occurs. As a result, an impediment for an active life appears to be that the participants find it difficult to anticipate the future.

Lack of knowledge and learning capability. Many of the participants said that they had lost previously obtained knowledge and that this had something to do with their mental problems or treatments. Moreover, it was difficult for them to catch up on lost knowledge, and it was even harder to achieve new skills that employment demands. Many of them wanted to learn the necessities of living an active life in society, but they thought that their limited learning abilities prevented them from accessing to regular educational programmes.

> 'I want to participate in secondary school, but it has to be at a slow pace. My memory is not good, nothing registers and I am worried about that. To remember is important! It is hard to know, but maybe it is because of the medications?'

To suffer from memory loss and the disappearance of prior acquired knowledge seemed to be very worrying. This results in insecurity and impediments for an active life.

Earlier memories and experiences predominately consist of difficulties. All of the participants described that their present situation had a clear connection to earlier childhood experiences. For some of them, a number of tragedies had occurred simultaneously and they had never felt popular or even accepted by others. Furthermore, some recalled experiences of difficulty in judging consequences of actions. The participants were aware what the hindrances were, but had a hard time dealing with their own difficulties.

> 'My parents died when I was in the middle of a divorce and I was also involved in a car crash. I have never heard that I was good at anything. I have always found it difficult to make myself heard'.

Lack in motivation and inability to leave the past behind appears thus to be impediments for an active life.

Worrying about reasons for being mentally ill. The participants' lack of knowledge of their own mental illness could perhaps be a further consequence of memory impairment.

> 'To find out how my parents have been could provide answers and increase the knowledge about my own disease. To obtain a diagnosis could be a relief'.

The lack of knowledge about the cause of mental illness became in fact so intrusive on everyday life, at least for some participants, so this also appeared as an impediment for living an active life.

It's difficult to develop an interest in other people. Some participants in this study gave the impression that they had no interest in having contact with other people. Other people did not appear to stimulate them in any way nor did they believe or have the confidence in themselves in order to give anything back to anyone else. The participants were thus not especially active in making contact with other people. It was mostly the instructors at the centres who often initiated interpersonal relationships.

> 'Maybe I'm not interested in socializing. I feel empty, everything is difficult! Don't fit in, it doesn't matter what I do'.

Accordingly, the participants seemed to have difficulty in establishing relationships, especially with the opposite sex. In addition to this, several of them also said that they found it hard to spend time talking about everyday things or general issues. Their initiative to establish contact was only in relation to something they needed, other than that, they often avoided contact. In order to have the ability to create relationships, one has to possess the ability to direct interest towards someone else and to sometimes give up standards and values on how relationships are created. This seems, however, to be difficult or almost impossible for the participants in this study. Many of them avoided new relationships and, instead, concentrated on protecting their honour or value systems from being affected. At the same time, they talk about the feeling of being on the outside.

> 'I have always found it difficult to socialize with others. Maybe I don't want to drag them into my world. I find it difficult to chitchat'.

Difficulty in developing an interest in other people seems thus to be an impediment for keeping company in an active life.

Comprehensive understanding

Alienation as main impediment for living an active life. The six tentative interpretations, highlighting different impediments for an active life, could also be interpreted as variations of alienation. The identity issues, which were suggested in the first interpretation, may contribute to difficulty in anticipating the future (which was highlighted in the second interpretation).

Furthermore, the lack of knowledge, the emphasis on earlier difficulties and the lack of cognizance about the reasons for being long-term mentally ill (which was suggested in the third, fourth and fifth interpretations) also make it difficult to share everyday life with other people. During such circumstances, the participants seemed to be unable to develop an interest in other people and benefit from earlier experiences and problems that were highlighted in the last tentative interpretations.

To be a part of a rehabilitation programme can, if all goes well, lead to a sense of community involvement. However, the participants in this study appear to, unfortunately, continue the process of alienation, despite their knowledge about what they need in order to live an active life.

The starting point for this study was based on a previous investigation, which concluded that people with long-term mental illness can express what they need in order to obtain increased quality of life. However, they lack initiative to make the necessary changes in their lives (9). Consequently, the aim of this study has been to further analyse and describe how long-term mentally ill people experience various impediments for living an active life. Alienation has been found to be a common factor amongst all of the identified impediments.

The feeling of alienation amongst severely mentally ill people has previously been described as existential loneliness (14). This phenomenon was described as a sense of being an outsider, alienated from others, even if you are amongst other people. Furthermore, the only people experienced as 'friends' were often professional caregivers. Hence, it seems fair to assume that alienation is a main impediment for an 'ordinary' active life for people with severe mental illness.

Discussion

A contradictory self-image

This study demonstrates how long-term mentally ill people attempt to influence their difficulty in living an active life through increased independence, self-control, control over one's identity, abilities, brooding about disease, life and relationships with others. Pejlert (1) has demonstrated in her study that patients are deeply involved in solving their own problems. This has also emerged within this study, in which the participants' thoughts and speculations revolve around self-image and identity.

Their ideals are contradictory; on one hand, they see themselves as perfect, unique, independent individuals and on the other hand, they show a great need to be accepted and to be the centre of attention. The participants want to be liked by other people although they live in isolation.

There seems to be a contradiction amongst the participants, in that they want to be accepted into normal circumstances and be accepted through rehabilitation. They were aware of the unspoken rule that one has to function socially. The participants in this study are above all, interested in gaining attention, but are unsure of whether or not they are good enough and how to stimulate this interest. Seeman (15) talks about social alienation consisting of being a stranger to one's surroundings and oneself. This was also confirmed within this study through the participants' experience in being strangers to themselves and others.

To obtain an existence of predictability

Lindell (16) suggests that the mentally ill patients' highest goal is to organize their every day life and to become financially independent. The participants in this study have a desire to have a predictable existence by obtaining their own apartment, daily routines, employment and financial independence. As a result, they believe that they can predict their future and gain control over their existence. Their vision of the future is very concrete with their drive for control, but at the same time, their goals are relatively high, for example, the goal of becoming self-sufficient after many years of sickness.

Other contributing factors that have resulted in not being able to think about the future could be the professionals' attitudes towards their limited opportunities for improvement and opportunity to become ordinary citizens, despite having a chronic disease. Hansson-Scherman (17) suggests that all chronic diseases result in gaps in the history of life. Furthermore, she comments that individuals with a chronic disability experience different stages; participation in everyday activities takes for granted that rehabilitation will occur, the desire to be oneself again, uncertain if things can be like before, trying to have a positive attitude of oneself despite the decrease in ability to function. This does not coincide with the findings within this study. They do not even talk about rehabilitation or the future, possibly only in terms of that time needs to pass by order for them to have the ability to look ahead. They fall back on the difficulties they have experienced and do not mention any positive experiences either before or during their period of illness.

To have insufficient memory and lack of knowledge

Other anxieties that affected the participants' opportunity to live active lives include their experience in losing their memory and ability to learn new things.

Lundin and Ohlsson (18) comment that psychological disabilities result in cognitive disturbances in the form of short-term memory difficulty, poor concentration and lack in ability to process information. This means that the group has difficulty to absorb new information and apply themselves in life.

To have self-esteem and to feel normal

Bengtsson-Tops (3) argues that it is not only the individual's self-esteem that has a negative impact, but also other people's reactions that can be interpreted as exclusive and dismissive. The lack of control over reactions or feelings results in that people, suffering from mental illness, who feel uncomfortable in the company of other people. According to Pejlert (1), patients both fear and yearn after relationships. Their interaction and life with other people is all about watching over and observing oneself in relation to his/her surroundings and *vice versa*, but they make no effort to direct interest towards others. However, they are mostly preoccupied with being accepted and comparing themselves to others.

According to Goffman (19), giving up interest on the world can also lead to the relief from always having to make an effort to be 'normal'. To participate in a social environment and forming relationships is straining and can be a hindrance if it means that there needs to be an active interest in someone other than oneself as well as being prepared to reconsider ones' standards and beliefs. Seeman's (15) concept of alienation also means social isolation. This has resulted in the participants not wanting to be on the outside or wanting to be original, at the same time as they express they are relatively not interested in other people. They also speak about wanting a partner so that they can be accepted into the situations where couples interact.

Åström (20) comments that patients do not want to spend time with just anybody as they fear that people who are ill may drag them into their problems and make them sick again. This could be an explanation; however, perhaps they feel like they do not get anything back from likeminded people, as they have the same need to be acknowledged. The participants also mention that they have difficulty in engaging in small talk with other people, and they would rather speak about difficult experiences. In order to have the ability to converse about the weather, it is necessary to have the ability to avoid thinking about oneself and ones' own needs. Above all, there needs to be a degree of curiosity and fundamental interest in other people.

To be sick – a form of identity (stigmatization)

When the participants described their experiences in life, they focused on their experiences with their illness as well as the reasons for their condition and disappointment as to why they are as they are. According to Lindell (16), mental illness should not be obvious, but it is expected that one can talk about the problems without it being a problem. The participants talk about their disease as it is something in the past, but at the same time, base their stories on the times when they had obvious difficulties.

In previous studies, the participants comment that there is a connection between the circumstances in their upbringing with the unforeseen occurrences in terms of their disease. They believe that the reasons are predominately environmental which are also demonstrated in Lindell's (16) study.

According to Åström (20), 'patient togetherness' is uniting and acts as an active force when the topic of conversation is about illnesses. It seems like the experiences, from the illness period, that overshadow all other experiences. Could it be that these experiences also have a positive element for the individual through being unique and important? It is also remarkable how they could have been able to affect their own disease and its consequences. They do not talk about their abilities, qualities, capabilities or opportunities. They can only talk about their existence in concrete terms. Lundin (18) comments that people who have abstract thinking disturbances are not able to place themselves in a situation that they have not previously experienced.

Conclusion

Despite efforts towards social integration, the findings in this study strongly indicate that people with mental illness perceive themselves as an undesirable, vulnerable and a marginalized group. The participants' had little hope about their lives changing and worried about their future. Existential and social alienation does not only conceptualize their feelings of being marginalized, but also illuminates the consequence of seemingly persistent negative attitudes towards mental illness. How people with mental illness are accepted into society ultimately reflects the community's ethos, i.e., ability to understand, accept and to support people with mental illness. However, in addition to this, the findings of this study further suggest that the participants themselves strongly contribute to their own alienation through a contradictory self-image and attitude towards others, an incapability to imagine oneself in further situations and relationships as well as effects of their impairments in cognitive functions.

Lastly, preventing alienation on the interpersonal as well as the community level can be an area for knowledge development as well as a moral duty and primary goal for mental health care workers.

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Author contribution

Anette Erdner, Maria Nyström and Kim Lûtsén designed this study. Anette Erdner, Annabella Magnusson, Maria Nyström and Kim Lütsén contributed to data analysis and critical revisions of the manuscript. Anette Erdner collected the data and obtained funding and administrative support.

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Research Article

Variations in Views on Life of Persons with Long –term Mental Illness

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Abstract

The aim of this study was to gain knowledge of views of life from the perspective of persons with long – term mental illness. Since there is some doubt whether persons with long – term mental illness are cognitively able to express such views, the research design must be relevant to this aim and respectful of the integrity of the persons involved.

The study was based on an ethnographic framework involving photos and interviews with five women and three men. In this study, it was but the participants themselves who became photographers and thus authors of their own narratives.

The photographs were used as a starting point for the interviews. The interviews were analysed based on the phases of hermeneutic interpretation. Four main themes were found; Thoughts about God, death and the meaning of life, the meaning of relationship to others, animals give meaning to life without demands, things have a symbolic meaning for life. Together the four themes show persons with long – term mental illness have important existential questions and not anyone to share or discuss these questions with.

Key words: existential question, interview, photo, long – term mental illness, views of life.

Variations in Views on Life of Persons with Long-term Mental Illness

INTRODUCTION

Much has been written about the impact of long – term mental illness on a person's quality of life specifically a lack of meaningful activities and inability to take care of their daily needs (Nordenfelt, 1995; Lokensgard, 1997; Nystrom, 1999; Goldberg *et al.* 2003). Quality of life is a normative concept, yet difficult to define because it has both objective and subjective dimensions (Ruggeri *et al.* 2001).Yet, poor quality of life in persons with

long - term mental illness is often associated with low work motivation, poor self-perception, difficulty in establishing and maintaining social relationships (Beel, 1979; Nolan, 1995; Dixon *et al.* 2001). Moreover, mental illness imposes a social vulnerability and dependency on others to assist with matters concerning their democratic and human rights. As a consequence of these psychosocial factors along with a cognitive dysfunction, these persons become lonely, socially isolated and experience themselves as "outsiders" (Erdner *et al.* 2005).

Green *et al*. 2002, Pejlert (2003) and Lindell (2003) have found that persons with long - term serious mental illness are fearful of relationships but at the same time wish to share their loneliness with someone. According to Nilsson's study (2004) persons with mental illness have since they were children felt different from others. The persons in the study had maintained this mode of living, similar to a life philosophy and something to strive for yet they longed to be like others. They have, according to Nilsson (2004), lived estranged from society under their whole life. In other words, feeling as a social outcast constitutes a basic view towards life; something that may confirm their identity of not being like others and their pessimistic view of the possibility of changing this identity. According to Wiklund (2003); Nystrom *et al.* (2002) persons with serious mental illness have a longing for human contact and closeness that they also avoid. This void in life can be described as existential loneliness, not uncommon for most other persons with mental illness (Nystrom 2002). In the studies by Erdner *et al.* (2002) and Magnusson (2003) it was shown that these persons understand that they would ”feel better” if they had the ability to form good relationships with others yet avoid opportunities to make attempts do so.

Although existential loneliness may emerge in mental illness, people in general can experience existential loneliness and have a need for spiritual comfort during different passages in life. Not only mental illness but also other life crisis raises questions about the meaning of ones existence. Although the concept of spirituality is commonly identified with religion, it may also include non-religious beliefs and deeper thoughts about life and the human existence.

Several studies show that spiritual and religious questions have importance for psychiatric treatment and a central component for recovery from mental illness (Rogers *et. al.* 2002 ; Corrigan *et.al.* 2003; Yangarber - Hicks, 2004; Koenig, 2004; Koslander & Arvidsson, 2005) contend that spirituality may help people with serious mental illness in that it may provide a framework for understanding one’s disability and add meaning to one's life. Wilding *et al.* (2006) conducted a Heideggerian phenomenological study that showed that spirituality became vitally important to persons when they became mentally ill. Lindgren and Coursey (1995) also support the view that spirituality can be an important component in the recovery from mental illness. However, there may be a problem discerning whether questions or expressions concerning religion and spirituality are related to psychotic symptoms or to vital questions that relate to ordinary life. Lindgren and Coursey (1995) point out that professionals must have the necessary skills and knowledge in order to distinguish psychotic symptoms from spiritual concerns. Fallot (2001) investigated spiritual and religious questions in a group of persons with mental illness and found that these are the same as they are for persons in general. The above studies indicate that a life crisis or a persistent feeling of being alienated awakens existential concerns and the need for spiritual comfort.

Views on Life

The philosophy concerning a person's view of life, as applied in this study, has both existential and a sociological components. The fundamental argument for this approach is that there is a reciprocal relationship between a person's view on life and her social and existential experiences. Our epistemological assumption is that it is not possible to gain knowledge i.e., understand a person's view of life from only one perspective. Even though an individual person's view of life is unique, some patterns may be found that could contribute to a deeper understanding of the complexity of living with mental illness.

Kallenberg and Larsson (2004, s 74) suggest that a view of life is a composition of a person's unique experience of the life that she or he has lived *and* live in.

Thus, the concept of view of life can theoretically be closely related to existential concerns, and spiritual needs (Jeffner, 1988; Blennberger & Nilsson, 1998; Bråkenhielm, 2001). Existential concerns usually emanate from a person's need to create meaning of their life
(Stifoss – Hansen & Kallenberg, 1996; Jeffner, 1988).

A person's thoughts about human beings and the world influence their general perspective about the order of things. Religious beliefs, personal philosophies and experiences are important components in the formation of a person's perspective (Jeffner, 1988) and self-identity. According to Andersson (2006) this means that the beliefs must have significance for *what* is assumed as important about humans and reality, resulting in a *selected description* of human beings and reality. But a perspective could also have significance for *how we interpret* what has been selected as most important entities and experiences in life. In the second case we could talk about an *interpreted description*. Such assumptions that gives perspectives in the way described here, comprises a set of "theories about the human being and the world" (Jeffner, 1988). These beliefs/theories or questions we recognize as more or less intellectual , for example, what is the meaning of life? Where is the beginning of the world and where does the universe begin? (Stifoss Hanssen & Kallenberg, 1996) or a question such as, "if God exist why do I suffer?

A person's feeling of being a social outcast can conceptually be understood in terms of alienation. Alienation can either be seen as a process involving many factors but also as a basic state of being in the world. Seeman (1976) suggested that alienation can be understood as an umbrella concept that includes six dimensions: (1) powerlessness, (2) meaninglessness, (3), normlessness, (4) social isolation (5) self-estrangement and (6) cultural estrangement. Seeman did not offer any logical relationships between these dimensions yet proposed that each could be useful in social research.

Mackey and Ahlgren (1977) definitions of three of Seemen's dimensions of alienation in their study of adolescence and alienation seem relevant to the study of views of life from the perspective of persons with mental illness: *Self-estrangement* describes the discrepancy between actual and idealized self. *Powerlessness* reflects fatalism, pessimism, and a perception of losing control over one's own life. *Social isolation* is a lack of intimate relationships, such as with friends, thus leading to a feeling of loneliness. *Meaninglessness* according to Mackey and Ahlgren (1977) study, "characterizes youths who perceive little or no relationship between what they learn in school and what they will do in the future." Applied to this study, meaninglessness suggests that persons with serious mental illness perceive little or no relationship or meaning between what is possible to change and the future.

If the data in the present study can be interpreted as consisting of theories/beliefs giving a perspective on life and reality, and if this perspective could be explicated in terms of self-estrangement, powerlessness, social isolation and meaninglessness, this could be described as a distortion in a person's perspective towards life. Thus, in order to understand what it means for a person with mental illness to feel alienated, questions such as what they value and how they look upon others and themselves in relationship to society need to be asked. Since spirituality, as discussed in this article, seems to have an important place in a person's value system, this must also be included in an empirical investigation.

AIM

Thus, the aim of this study was to gain knowledge of views of life from the perspective of persons with long - term mental illness. Knowledge of variations in the views of life of these persons may also add a new and important understanding of alienation. Since there are some doubts whether persons with long - term mental illness are cognitively able to express such views, the research design must be relevant to this aim and respectful of the integrity of the persons involved.

METHOD

The epistemological foundation for the design of this study is the assumption that an understanding of a person's view life can be gained from his or her own narratives. Moreover, these narratives can reveal experiences, although unique for each person, that can possibly cast a new light on difficulties that these persons have in feeling accepted in society. The study design builds on the basic features of ethnographic research (Hammersley & Atkinson, 1995):

- The emphasis is on the nature of a specific social phenomenon
- An investigation of a small number of cases
- Analysis of data that involves explicit interpretation of human behaviour or expressions
- the use of theory to interpret or explain a social phenomenon

Selection of Participants and Collection of data

Five women and three men were asked if they would be willing to participate in the study. These women and men were recruited from three day-centres for persons with long-term mental illness living in the community. The day care supervisors were contact persons who left written information to potential participants, arranged information meetings and the location for meetings between the researcher and the individual participants. The inclusion criteria were

- a psychotic illness that has been formally evaluated as causing inability to perform activities of daily life without professional support
- cognitive able to understand the principles of informed consent and willingness to participate in the study
- between 18 and 65 years old
- not suffering from an acute psychosis or neurological illness

In order to encourage a dialogue rather than a one-sided interview, a method that can be related to photographic ethnography (Harper, 1998) was used. A well-known study of Bateson and Mead (1942) serves as an example of this method. In their field study of a Balinese mountain village the anthropologists collected mainly photos, film drawings, sculptures as data in order to gain an understanding of the culture and social life. Many more studies use the camera to photograph specific situations and phenomenon. In this present study, however, it was not the researcher behind the camera, but the participants themselves who became photographers and thus authors of their own narratives. The idea behind this approach was that the photographs would help to reach a level of the dialogue and prompt reflexivity. It also relates to the theoretical discussion of the function of a view of life, as it gives a material expression of the person's *perspective* in the photograph.

The procedure was as follows: At the first meeting with the researcher, the participants were each given a disposable camera and asked if they would be interested in photographing objects, situations or persons that were important or meant something to them. Each camera contained 10 slides. The participants were also guaranteed that these pictures would be held confidential and not revealed without their permission.

At the second meeting with the researcher, the film had been developed and the pictures were the starting point of a dialogue between the researcher and the participant. The participants were asked to describe what they thought about these pictures. The participants could easily reflect on the pictures and the meaning they had. Each dialogue, which lasted about one hour, was then transcribed verbatim into text for analysis.

The photographs were used as starting point for the interviews. The informants decided on the order of the photographs would come and what they wanted to say about them. Most of the participants chose to say something about each photograph or to describe all of the photographs in what they represented.

The participants in the study were very eager and enthusiastic to photograph and needed about one week to take ten photos. One man and one woman needed six weeks and one man declined to continue because of a separation that worsened his health. All of the participants photographed their daily activity (work cooperative), yet one participant only took one photo of this milieu. Co-workers, instructors and objects were common subjects. Two participants had photos of their family.

Several participants had arranged objects and situations in order to reflect their feelings, situation and behaviour. For example, one woman had photographed herself in a "party" situation with a gown especially bought for the study.

Ethical considerations

The Regional ethics committee, Stockholm (2004/5:9) approved the study.

Informants who responded to the advertisement, and who met the inclusion criteria were contacted by the main investigator (AE) by meeting and telephone.

They were informed orally, as well as in writing, about the purpose, content and extent of the study and were guaranteed that neither they nor their place of daily occupation would be identified. They were also informed that participating in the study was voluntary, that their information would be handled confidentially and that they could terminate the interview if they were unhappy with any aspect. They were also informed that photos and interview tapes would be kept in locked storage.

Data-analysis

Data-analysis in principle follows the phases of the hermeneutic process as outlined for example, by Soderberg *et al.* (1999) naive reading, structural analysis and a holistic interpretation of the participants' views of life. Naive reading is the first step in interpretation. A structural analysis includes to examinations of the parts of the text to explain what and how it expressed. Four themes were found. The interpreted whole is a critical interpretation based on the pre- understanding, naive reading and structural analyses and concern to obtain a deeper understanding of what the text conveys.

RESULTS

Themes

Thoughts about God, the meaning of life and death

This theme describes the participants' thoughts about the meaning of life and what happens after death. "To believe that life has a meaning", as one participant said, "makes me feel healthier and safer". "It is life that creates illness , no person is born with a psychiatric illness". The participants described a type of spirituality that bestowed a feeling of peace and stillness that only exists in "the beginning and end of life". Spirituality seemed to represent a sort of cleanliness with no room for illness. Death was a frightening thought, yet one participant expressed, “The moment of death the human being enters into spirituality.

The participants described a fear of death, specifically to”disappear from earth and everything ends.” Not to exist means to be”extinguished – no one will remember me and I will be forgotten”, as one participant said. Another thought it would be best to ”just disappear, not to have a grave or gravestone, no one is coming to visit that anyway because I am not that important”. Yet another informant believed that a gravestone gave a small chance that someone would remember.

The participants’ description of their feelings of loneliness and the risk to be forgotten after death seems to give them much death anxiety. To find a meaning with their lives before death was therefore important. If the question of the meaning of life were not answered it would mean that death would not be peaceful. A desire for eternal life or life after death, according to some of the participants, would give them a possibility to be”seen”.

To have a faith in God was important although the participants felt that God had failed them when they most needed him. Instead, they believed that God has punished them and turned His back on others. This is why, as one participant said, he is seeking a new faith. Another participant said;”you can’t be without a faith because this leads to self-pity and a shorter life”. “To be an atheist burns you out.”
These examples of the participants’ thoughts indicate that to feel that life has a meaning does not need to be religious. Moreover, one is not born with mental illness.

The meaning of relationship to others

The participants' lives could have become different if when they were children there had been more harmony, especially between their parents. They would today have more self-confidence and trust in others. One of the participants said that if her mother had had a ”guardian angel” she would have been ”happier” and then she herself would not feel as “broken” as a person with “schizophrenia feels”. The participants attempted to reach reconciliation with their experiences from early life and to find a meaning in the present life. Most participants expressed distrust in others because they had ”befriended the wrong type of persons” or had negative experiences in relation to others. All of the participants said they would rather related to animals than people, they feel more at ease and peaceful. They viewed animals as having the same value as people.

Animals give meaning to life without demands

This theme describes the participants' feelings about their relationship to animals. Animals (pets) bestow meaning to life in an undemanding manner and are of equal value to human beings. One participant strongly emphasized - “animals are not meant to be eaten of moral reasons”. Most of the participants said that it is easier to be with animals than people because pets are “in comparison with people, pets are more loyal and adjust themselves according to a person's needs and health.” A reason for this was, “pets do not demand anything but at the same time are dependent on one” and thus “I feel needed and my care is appreciated”. The participants described a mutual feeling of well-being between themselves and animals. One participant eloquently described this relationship; if “I am not able to function, then my pet can not – he stops playing and doesn't show any happiness either and becomes sad”.

The meaningful relationship the participants had to their pets would only exist as long as they were alive, which meant there is no one that can pass on their memory, a cultural activity that their pets are unable to do. Their pets can neither transfer grief or happiness even if they have feelings.

Things have a symbolic meaning for life

This theme describes the participants' thoughts on the meaning of the objects they photographed had on their lives, which goes on. His or her isolation from other people means that there is no one that can carry this symbol. The lack of trust in others, which was common for all participants, makes daily life more difficult because no one is, ”good enough” to inherit valued objects. The participants talked about these objects as if they were part of themselves. To give away an object would mean that they would lose a part of themselves.

Objects are symbols that can create feelings of harmony. A participant felt that “angels” helped her to be”more whole” and”not so tattered”. She explained; “angels want what is best for me”. Symbols, such as angels, can serve as bridges between themselves and others. To purchase and to become the owner of objects meant that they were like anyone else reflecting a wish to connect with the material world. Yet, it was important that objects should”not to be too many because this would create disarray and chaos” in their lives. The computer, for example, is a link to others and something that they themselves could control.

HOLISTIC INTERPRETATION

Four themes have emerged, the participants' thoughts about their relationship to God or faith, other human beings, animals and material things. All of these themes relate to life and death and reflect variations of basic views of life that we may all have. Crisis in life often means a transition and with support of friends, family or professionals, a person can carry on. Based on the participants' reflections on their view of life, however, it seems that mental illness creates a void in life that they perceive never to change or be replaced with meaningful moments or activities. The passages in life they could relate to and feel an affiliation with was birth and death. Their spiritual search, thinking about why and how life had become for them, was an attempt to fill the void between birth and death and thus finding a meaning for their existence. These thoughts were important, especially concerns about their own death and belief that they would be eternally forgotten. Spirituality gave them a feeling of harmony, inner peace, and a mental balance and would help them not to worry about "being a social outcast".

The themes in this present study indicate that persons with mental illness may want to feel a connection with the world they feel alienated from and to find meaningful relationships yet on their own terms. To be seen as mentally ill persons enhances the gap between how they perceive themselves and their ideal selves. According to Granerud and Severinsson (2003) persons with mental illness who experience lack of acceptance have little autonomy or possibility to determine their lives in general. The findings in this study concur in that the participants perceive confirmation or acceptance as a concrete manifestation. This is important in order not to forfeit their identity as *persons*.

Selander (2003) in an autobiography has described that a precondition for recovery is to exist in the present. Thus it is necessary to live here and now and to focus on oneself as a person. Other studies (Erdner et al., 2002, 2005; Lindell, 2003; Nilsson, 2004) point out that persons with mental illness have little interest in a mutual confirmation in their relationship to others. In this study, men and women explicitly expressed that they would rather relate to animals (meaning pets) because they experience a feeling of well being when they are with them. Together with animals, persons with mental illness can experience themselves as being of value and needed, i.e., a mutual relationship of giving and taking. The pets need to be taken care of, regardless of the owner's health, which strengthens their feeling of being useful and thereby gives them a more positive outlook on life.

It could be that the "ideal self" presents itself in these persons' lives via their relationships to pets. Their feelings of not being useful and low self-esteem lessened when they had in their eyes, a meaningful activity. Since they viewed that animals had the same value as humans, the reciprocal relationship could potentially serve as a link to the world the person longed to belong to in spite of distrust and misgivings. Pets, according to Topor (2001) create new topics for conversation for persons with mental illness and thus can shifts the tendency towards self-preoccupation to an interest in the surrounding world which in turn would lessen the feeling of not being like others. Yet in this study, the participants perceived that their pets would not care for them after their death and thus it was important to find a meaning *in* life in order not to be forgotten.

One meaning of life could be to have a faith that would also give them a longer and healthier life. According to the participants' perceptions, in a communion with God or other higher Beings, mental illness does not exist. Rogers *et.al.* (2002) suggests that faith and spirituality endorses hope and improvement in mental illness. To have faith is a way to move thoughts from self and the inner world to the surrounding world. Faith seemed to mean that the participants would feel a relief from constantly shielding themselves from the attitudes of others and not being able to do anything differently. Although they expressed a distrust and deep disappointment in God especially when life is most difficult they grieve for their lack of faith in God. This illuminates the view that God is something that serves them rather than that they feel an obligation to their God.The participants believed that a grave was a symbol to be remembered by others, the significance in relationship to others. However, for these persons, to think about this was discomforting. An important decision for the persons in this study was, therefore, whether they should have a grave or not. Their worry that life could end at any time seemed to increase their thoughts about what they had done in life – the empty space can not be reconstructed or filled with relationships that have not existed. The participants were also concerned with who would inherit their valuable possessions since they did not have anyone close to will these to.

CONCLUSION

The focus of this study has been the thoughts about some mentally ill persons' thoughts about their relationship to others, to God, to animals and to things. They have good relationships to animals and things and not good relationship to God and other persons. This seems to support the idea of alienation: estranged from human relationships and relationship to God. "Things" and animals are stand-ins for relationships that they do not have.

For the persons who participated in this study, life has three phases, birth, an empty space and death. Views of life contained questions about the consequences of not having a faith and their doubts about God, thoughts about their own death and not being remembered, and the importance of animals. These men and women longed for meaningful relationships with others yet withdrew from the possibility of forming close relationships. Animals i.e. pets diverted their attention and their feelings of existing as a social outcast. To have a faith gives spiritual comfort and a healthier life.

An important conclusion of this study is that it is apparent that these persons did not have anyone to share or discuss their existential questions with. Therefore, it may be important to create room for and offer sensitive encouragement for persons with mental illness to express and reflect on their existential concerns .This may alleviate or lessen the feeling of alienation.

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Cautiousness-basic attitudes in mental illness

Research Article

Cautiousness - a basic attitude towards life for persons with long- term mental illness living in the community

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Abstract

The aim of the study was to explore basic attitudes to life as experienced by persons with long-term mental illness living in an urban Swedish community. The study was based on an ethnographic framework using self-photography and conversational interviews with five women and three men. In an attempt to illuminate the informants' attitudes based on their experiences, they became authors of their own photographs and narratives. Analysis of data followed the phases of the hermeneutic process; naive reading, structural analysis and a holistic interpretation of the informants' basic attitudes towards life. The theoretical assumptions of views of life based on Jeffner's three components; persons, animals and nature, and object. The findings reveal that the informants had an inadequate trust in their fellow beings and the world about them. This characterised their basic attitude to life as being cautiousness. The methodological approach shows that using photography was a natural way for the informants to describe how they experienced and perceived reality. Using photographs could also be applied as a way to help the professional carer to encourage these persons to talk about their daily lives and thus give appropriate support.

Key words: basic attitudes, photography, mental illness.

Cautiousness- a basic attitude towards life for some persons with long- term mental illness

Introduction

Quality of life and values of life [1] are the sum of all the contexts in which a person lives. Once the interplay between family, friends, work, leisure, society, history, nature and religion wavers, then pesons suffering and vulnerability arise. For person with long-term mental illness such interplay has broken down, and they are characterised by existential loneliness
[2-5]. Quality of life studies of person with long-term mental illness have been brought to the fore in recent decades, partly because the number of known individuals is large, 40,000-45,000 (Swedish pop 9m), and partly because method of care has changed from institutional to independent living, and also because, despite considerable undertakings, these person have difficulty in coping without the work carried out by health and care services ([6-7]. Many studies exist showing that person with mental illness wish to but have difficulty in establishing relations with other person [8-14].

They fully realised that relations could add purpose and improve their wavering self-esteem, but felt unable to apply their capabilities [15].Their incongruity is further seen in their views of themselves and their unimportance in relation to others. The writers [15] showed that person with mental illness experience themselves as vulnerable and marginalised, while at the same time escalating their isolation via their own negative attitudes to mental illness. Being isolated – being an outsider – or not being accepted provides limited autonomy and is of great importance to their lives in general [16].

The studies accounted for here show that the complex of problems revolves around relations and the mentally disabled, and their view and understanding of themselves as pesons beings.

Theoretical points of departure

Thus what is considered here and is the focus of this study is the individual's cognitive awareness of his or her situation and particular way of feeling about this situation, i.e., basic attitude to life.

The Swedish philosopher and theologise, Anders Jeffner's [17 p.13] definition of basic attitudes to life, a component in his theory of views of life is used as the theoretical basis in this study:

> *Outlook-on-life is the theoretical and values-related assumptions making up or having great importance for a general picture of personify and the world, and which creates a central system of values, expressed by an individual's basic attitude to life.*

This definition is based on three components: *theories related to personify and the world/universe; central systems of values;* and *basic attitude towards life.*

The component *theories related to personify and the world* deals with the general views of persons beings regarding the structure of existence, and is based on religious, philosophical and scientific experiences, plus personal experience [17] . The *central system of values* component deals with the understandings individuals have as to what is important in life, its meaning and how person relate to it [18-19] .

An individual's frame of mind, their feeling for or attitude towards life, is expressed by basic attitude to life and is based on *theories of personify and the world* and *central system of values* [17, 19 p.27 ,20-21]. Basic attitude to life is expressed in the form of the interwoven keynotes faith, hope and despair. This is displayed as a composite state of mind, attitude or way of reacting that is positive or negative; a sense of feeling that is difficult to give a name to [19 p.11].

The writers [18] wrote that spontaneous and latent feelings exist where the latter are well established and existential in character. These may be will-work-out or won't-work-out feelings, the feeling that opportunities exist, or be confined to seeing difficulties and problems. Jeffner states that basic attitude to life is enduring and optimistic when life is free from problems, but keeping this positive is difficult once problems arise [17].

Substantial and comprehensive studies have been carried out to rate the basic attitude to life and values of individuals, but not as regards mentally disabled person as a specific group [21]. Persons with long-term mental may have a basic attitude to life that influence their feelings of being a part of society or not. Gaining a deeper knowledge of the basic attitude to life of these persons may also lead to re-thinking psychiatric health care services and develop support that strengthens their self-determination and quality of life.

Aim

The aim of the study was thus to explore basic attitudes to life as experienced by persons with long-term mental illness living in an urban Swedish community.

Research design

The research design was built on a qualitative approach in which informants participated in gathering data in the form of photographs and stories relating to them [22]. Interviews were in the form of conversation to avoid any asymmetry of power [23]. In comparison with conventional conversations, such interviews are characterised by openness towards the perspective of the informants themselves. The photographs opened the opportunity for conversation where informants could choose what they wished to talk about on the basis of study focus. The role of researcher was to provide critical attention to informant stories on the basis of both scientific and ethical attitudes. Data material was treated confidentially to uphold the integrity of informants and photographed individuals. The Regional ethics committee, Stockholm (2004/ 5:9), approved the study.

Selection

The heads of three different activity units were contacted and asked if they could help by distributing written information on the contents of the study to prospective participants. Interest in taking part in the study was expressed by three men and five women, and they were contacted to agree on time and place for personal information.

They were asked if they would be interested to spend a week and photographing objects, situations or persons that were important or meant something to them. The researcher (author) also informed them of her wish for individual dialogs relating to photographs taken.

Several of the informants asked further questions on photo contents to be sure of understanding the task. Here the importance was stressed of informants making the choices themselves. Whatever was photographed was what they considered important to photograph.

Gathering of data

Films were developed to receive two copies of each photograph: one for informant and one for researcher. Time and place for an interview was determined between informant and researcher together. The majority of informants took approximately 10 photographs; one took six and one 23.

Each interview was recorded and launched by each informant being given their photographs and asked to talk about them in order of their preference. Some of the informants had taken pictures in a specific order to show how a typical week might appear. Others had carried out more spontaneous photography. Two informants felt they had failed to take the pictures they had wanted to take and were given the opportunity of taking further pictures.

Data analysis

Data analysis in principle followed the phases of the hermeneutic process as outlined for example by [24]: naive reading, structural analysis and a holistic interpretation of the informants' basic attitudes towards life. Naive reading is the first step in interpretation. A structural analysis includes examination of specific parts of texts to explain what is expressed and how. The interviews were analysed and structured according to a matrix (fig 1) based on [17]. three components of persons, animal and nature, and object. A modification of Jeffner's theories was made in order for the analysis to reflect an etic perspective [25] on how the informants viewed themselves and their relationship to their environment.

Results

Analysis of the results of a total of 97 photographs and interviews with the eight informants was collated and presented according to the matrix. Each perspective starts with a description of the photographs followed by a summary of what informant said. All of the informants had illustrated their daily life; some had taken self-portrait, photo on their home and a few photos of their family. There were many photographs taken of daily occupation centre and the instructors there. A few persons had arranged the photographs into different scenes. These informants had not taken any photographs of their home, family or daily occupation centre.

Self-Portraits

Three informants (women) had pictures taken of themselves (seven pictures altogether). One of the self-portraits shows a woman in a party hairstyle, generously made up and wearing a sequin dress.

The second shows a woman of 35 with short ash-blond hair, wearing a T-shirt and military-style jeans. The picture was taken in a child's room with drawings on the wall depicting a dog, the sun and a teddy bear. The informant stands in front of a pine bed with a stool close by appearing to serve as a bedside table.

The third woman took pictures of herself active at the work and activity unit she attends. Here the informant has her hair set in a ponytail and her facial expression is resolute and strained.

What informants said about themselves in relation to the photographs

Both the three self-portrait informants and the other five informants talked about themselves on the basis of what they had experienced, how they currently live and how they would like life to develop in the future. They related what it means to have an identity, how an individual's identity is formed, what is entailed by suffering and well-being, and the importance of earlier experiences in relation to their personal development.

The search for a personal identity

The first informant who dressed up for the photographs said:

"It's like when I was small and got dressed up. My mind feels split about it – on the one hand glitter and sparkle is fun, on the other I don't want to be noticed. She continued: "No problem there though, since I don't go to parties or meet people." Her aim is womanhood, to feel good and be happy. Her aspiration is to wake up feeling life's working, "to do something for myself and not always for others." Another informant related how important it is to do things for yourself and not just for others. Having opinions differing from others is discomforting.

The informants said making something of life is important; to find meaning since life can end at any time. Also important is independence, along with building internal security, having patience with one's self – something that takes time. One informant said she had to live a restricted life, trying out new things but at a pace to suit her capacity. Another: "I find gauging closeness and distance difficult, I'm abandoned and alone." One of the informants said it would be a relief to be guaranteed eternal life, to be someone in relation to others, to feel affirmed, to be a distinct individual.

System of norms

Day-to-day life has to be filled with something secure and pleasurable, said one of the informants; keeping promises, avoiding criminal actions, being a Swede, being employable, functioning socially, being pleasant and of importance. External order can give internal order. Also of import is the development of traditions; reasonable demands cannot always be met. A further informant related: "Keeping things in order is hard, I can't cope with day-to-day contacts."

Description of photographs – family/friends

One of the informants had photographed a 40-year-old man together with two children. The photograph was taken in a room with colourful child's drawings on the wall, depicting a large mushroom with a charming sky and a path making up a never-ending tunnel. A woman informant photographed a man lying turned away on a sofa. In front of him is a bag of crisps and at the edge of the sofa are a number of ornamental elephants. Several of the informants portrayed children, with one man showing a 35-year-old woman with a baby. Women took the other photographs of children.

One family/friends photo showed a man sitting in an attic at a computer, another was taken of an older, very pale, man in his sick bed. One of the women informants arranged and photographed an older woman with a large bouquet of flowers in her arms. A male informant photographed a group of middle-aged women and men. The picture was taken in a classic home environment with 19th century sofas, crystal chandeliers, large antique candleholders with lit candles, and fine carpets and tapestries with various motifs. The table is set with an early 20th century coffee service.

What informants said about friends/relatives in relation to photographs

Being a family – having a relation

One of the informants – a single parent – related that she has three children, one of whom lives with her. The three children have two different fathers. Her former relation to their fathers was destructive. For two years past she has lived with a woman she can trust: "I don't need to put up any false front for her."

Another informant told of her child in adoption and the loss she felt after natural contact with him. She said, “The day-to-day squabbles don’t exist.”

One of the women informants wanted to photograph her boyfriend since he was important to her. “He cuts down my loneliness, but I couldn’t live with him – then I’d lose my own self.” It works out fine for shorter periods such as holidays. On the basis of the photographs, other informants told of former negative, destructive relations.

Several related how important their friends are. Two of them portrayed and talked about their brothers and sisters.

Importance of parents in relation to feeling secure

Several of the informants stated that above all their mothers provided a context, and compensated for what they were unable to give them as children. Mother was described as a “life-line” when they felt bad, despite her having been and still being “immature and childish with frequent outbreaks of rage”. “My parents have had different roles in different periods of my life.” Some suggested, “My father has merely been a provider of economic support”. One said: “parents aren’t to be reckoned with.”

Another had broken off maternal relations since the relationship was so destructive.

Importance of friends

One informant photographed friends and said these friends were close to him and that contact between them had been long lasting. Another told how she had girl friends but still felt alone. Some longed for friends but lacked them and did not know how to get the right ones.

Photographs of others

Some of the informants confined their photography to pictures of instructors from their places of work, and several – but not all – photographed work colleagues. Five personnel from work and activity units were depicted. One of the informants photographed psychiatric personnel, probably in one of their offices.

One photo differed from the others and was taken by a female. It shows a little girl with a rucksack, back turned to camera. She is walking away from the photographer along an empty street. The girl's estimated age is five.

What informants said about others

How informants experienced others round about them

A male informant took many pictures of his three instructors and praised one in particular. "He keeps me on track, he knows what's good for me, gives praise, never says no, I cheer up." One of the other two instructors is a friend who provides advice and help, while he feels the third makes him stressed: he's a bit grumpy and the things I do are wrong. The informants otherwise experienced their instructors as important – good-hearted, persons, supportive, boundary setters and respectful. "She is like an angel." One informant photographed a staff member in the psychiatric care service. The informant was dissatisfied with her treatment and felt she was not seen as a persons and that she was outside society.

Work unit colleagues compensate for lost time at school and discuss politics, economics, mental disabilities and social issues.

One informant felt harassed by both neighbours and friends; one friend was well- meaning, but the neighbours are not. The informants told of their relational difficulties, their difficulties when people got too close to them. Relations with men should give happiness, good sex, common values, sympathy, warmth and tranquillity; providing a feeling of mental and physical well being. One informant said she did not like team sports since these required fellowship, leaving her feeling insecure and uneasy.

The informant who took the picture of the girl on the road felt it had no meaning at the same time as she told of her incapacity, that she had missed something in life, that she is so poor at relations, that she has an inner insecurity and great need of control.

Photographs of animals and nature

Five informants had photographed cats, birds and a dog. The cats and birds were portrayed in the home environments of informants the dog was pictured outside. One informant photographed a bird-table with birds close by a classic red-painted cottage with a Swedish porch entrance. A couple of informants photographed potted plants. One photograph shows a wilted flower in a pot, while the others show two healthy plants, monstera and fern.

What informants said about animals and nature

Several of the informants had attempted to but failed to photograph dogs, cats and birds. Animals meant something to them and in cases where they were forced to get rid of their animals they were unwilling to say why. The informants felt it was easier to get along with animals than person, since animals provided meaning, were affectionate and adaptable. "If I'm not functioning then the cats don't either, they get down-hearted and stop playing", or "the dog adapts its daily rhythm to me". Their experience was that animals demand less than persons.

The informant who photographed the wilting flower said it illustrated his/her feeling of being wilted in particular situations, but also illustrated an interest for taking care of wilted plants and making them healthier. A form of reciprocal relation between informant and nature exists.

Photographs of objects

Informants photographed outdoor environments and housing, a church, shops, scaffolding, roads and an underground station. They also photographed work and activity units, a sickroom and various rooms in their flats. Several of them photographed pieces of furniture such as bookcases with e.g. reference books, crime stories, novels etc, along with sofas, beds and outdoor furniture. The bible was on one photograph. Also photographed were televisions, computers, jewellery, paintings and drawings, along with work machines and cleaning equipment. Many informants photographed cuddly toys such as teddy bears and elephants, placed on an armchair, sofa or bed. Some of the photographs displayed large quantities of odds and ends.

One informant photographed her home, the route to her psychiatric clinic and work and activity unit, shops she went to and her church. One male informant limited his pictures to his work and activity unit, while another had photographed not just his unit but also the journey there and back.

What informants said about objects

According to informants, work and activity units provided them with "a structure to life". Their photos gave a comprehensive picture of their daily life. Their photographs of budget and second-hand shops showed their poor finances and how they attempted to gain control over their private economic situation. Where the importance of person is measured in money, money has great importance. Being mentally disabled means being in the hands of the social services, psychiatric services and social welfare – something which provides a feeling of worthlessness.

One female informant photographed her mother's elegant apartment. An angel was situated above the bedroom door of this flat. The informant said: "angels are always nice to you, they like church just like my mother." Home is important, a place to be one's self, read and watch television. "I like my flat, that's where I eat, lie in bed and read Winnie the Pooh." The home mirrors the person: “If the flat’s in order, then I’m fine too.” By setting up a pair of loose antique bed ends, one informant wanted the room to look perfect for taking pictures.

Television was important, functioning both as leisure pursuit, company, escape from the everyday, and as a soporific. Several of the informants talked about the computers they photographed. They are able to use them to make friends and contacts in the world around them without having to meet person. “Web contact is easier. You can be yourself and don’t need to be exposed to surprises.” Wall cupboards and items such as paintings, shells, angels, glitter, teddy bears and necklaces are important items to them.

Discussion

The aim of the study was thus to explore basic attitudes to life as experienced by persons with long-term mental illness living in an urban Swedish community. The basic attitude to life component consists of person’s thoughts about the world and their systems of values. This is what was applied in the discussion as a framework for interpretation.

The search for personal identity and life’s meaning

The informants told how they searched for a meaning to their lives. Their wish is to make something of life: life is short and might end at any moment. Despite experiencing their life as limited they hoped to try out new things, but at a slow pace and adapted to suit their capabilities.

Important are: finding and accepting one’s self; being someone in relation to others; experiencing positive feelings and developing an inner sense of security.

As also is the need for relations with others. At the same time, informants were aware of their own loneliness, their fear of closeness to other person; leading to contacts with others expressing themselves in a different way.

Hansson showed individuals to be interested in and focused on making their lives clear to themselves, that persons are aware of their needs, aware that individuals themselves have to do something about it all [26]. Informants in the current study showed a degree of insight into their needs, but at the same time showed an inability to do anything about them. The reasoning [26] leads to the need for person to test their thoughts on life's meaning with others in order to be able to develop as individuals.

The inability of the informants to relate to other person resulted in only a few living in some form of partnership. Instead their parents supplied the life-security otherwise lacking. Despite their mixed experiences of parental destructivity and lack of presence, it is they (mothers) who provided security, context and crucial help in difficult situations. In relations towards other person, trust was of great importance if relations are to be meaningful. Some had difficulty in maintaining their own identity in closeness to a partner, and instead adapted themselves completely to their partner. Instructors at work and activity units had become very important to certain of the informants. A study by [27] showed that work and activity units reduce marginalisation and, according to [28], satisfy relations with instructors, which informants saw as cheerful, praising and angel-like.

Work colleagues with also satisfied the need for meaningful discussion whom informants could discuss and exchange opinions on social issues and their own situations as mentally disabled. Such talks provided them with knowledge of what others think, helping them to formulate their own opinions, increase their personal sense of security, while at the same time having conversations on a level not necessarily leading to deeper relations. Computers had become an important link between them as individuals and the outside world. Informants could use their PCs to develop friendship relations while they themselves as individuals decided when and how these relations could be maintained or terminated. Animals play a very important role for the informants, giving their lives meaning, as also studied by [28].

The informants appeared to find a sense of meaning in their accommodation, as also described by [29]. In his or her flats they do not need to dissimulate, be someone else; it is here they are able to be themselves. The person with long-term mental illness expresses both independence and fear of living in their own accommodation [30]. Their feelings of being insignificant and depreciated by those rounds about them because they are unemployed made it difficult for them to find a meaning to life.

Method discussion

The method of gathering data provided wide-ranging, substantial and in-depth material based on photographs and what informants related. The method promoted the autonomy and independence of the informants and encouraged their own choices and their own opinions.

Conclusion

The informants had an inadequate trust in their fellow beings and the world about them, and this characterised their basic attitude to life as being careful and cautious. Their wish was to be seen as functioning members of society. It is important for health care personal to realise that changes must take place on these persons' own terms and accept that any process may take a long time.

The photographs were a natural way for the informants to describe how they experienced and perceived reality. The focus was placed on their narrations rather than on the fact that they were interviewed. Using photographs could even be applied as a way to open up a meaningful dialogue that would help the professional carer to give support that is according to these person's own wishes.

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Figure 1

	Persons	**Animal and Nature**	**Objects**
Personal/ Social level	One self Relatives (Wife /husband, children, family, friends) Other (Fellows-worker, staff)	Pets Birds Plants	Interiors Furniture Household tools Computer/ TV Ornaments Activity units Psychiatric receptions Public buildings