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Förord

Under flera år arbetade jag som ekonom på en öppenvårdsenhet inom Karolinska Sjukhuset, specialiserad på traumatiska ryggmärgsskador, Spinalis. Arbetande och sittande mitt i verksamheten med rehabiliteringspersonal och patienter kring mig blev jag ofta en passiv åhörare av pågående samtal. Jag snappade upp diskussioner mellan patienter som handlade om vad för stöd/service/rehabilitering man hade ansökt om, hur mycket man hade fått beviljat och vad man inte hade fått beviljat. Ämnen såsom nivån på handikappersättning och skinnklädsel som bilanpassning flög förbi. Jag reflekterade över att patienter som satt och väntade på att t ex få ett trycksår omlagt inte primärt pratade om sitt medicinska tillstånd utan istället diskuterade andra samhällsinsatser, insatser som handlades av andra samhällsaktörer, någon annanstans, i en annan miljö.

Också rehabiliteringspersonalen engagerades i annat än rehabiliteringen. Det förekom, inte så sällan, att någon letade efter en patient som inte hade dykt upp på inbokad tid - i efterhand fick jag ofta höra att det hade varit förseningar eller strul med färdtjänst. Jag mindes också mina uppväxtårs somrar varav en del tillbringades på sjukhus i syfte att mina funktioner efter en egen traumatisk ryggmärgsskada skulle kontrolleras. Det handlade inte om någon märkbar försämring i mitt tillstånd utan kontrollerna hade ett preventivt syfte. Jag insåg att de nutida initiala slutenvårdtiderna innebar att vårdtiderna snart låg i samma omfattning som mina dåtida preventiva kontroller.

I denna flora av samtal speglades mina egna upplevelser kring hur vård, rehabilitering, stöd och service hade fungerat under alla de år jag levt med ryggmärgsskadan. Jag konstaterade att mina egna erfarenheter var inte bara mina egna utan tydligen många andras också. Tankar kring hur samhället är organiserat för att stödja alla individer som har drabbats av en traumatisk ryggmärgsskada tog form. En rad frågor dök upp. Vilka stöd finns egentligen formaliserade, hur kan man ansöka om dem och på vilka grunder beslutas om vem som kan erhålla stöden och vilka nivåer som erhålles? Hur har vårdtider sett ut över tid och hur avgörande är personkaraktäristika såsom skadans omfattning och nivå med avseende på de resurser som dessa individer använder sig av? Alla dessa frågeställningar blev sedan drivande och vägledande i mitt arbete för att skapa en tydlig bild av vilka samhällsresurser som finns och hur de används efter en traumatisk ryggmärgsskada.

Som doktorand fick jag möjlighet att fördjupa mig inom området. Föreliggande arbete utgör en licentiatuppsats baserat på tre studier. Ytterligare studier kommer att genomföras i syfte att sammanställas till en avhandling.

Min forskningsväg har varit lång och krokig och började på Spinalis dit jag rekryterades tack vare Med. Dr Claes Hultling. Mötet med Professor Åke Seiger innebar en introduktion, inneslutning och handledning i den vetenskapliga sfären. Docent Richard Levi och Med Dr Gunnar Ljunggren har även de handlett mig. Utan ert engagemang och vägledning hade jag inte kunnat förverkliga mina tankar. Tack! Från Karolinska Institutet bar min väg vidare till Lunds Universitet, Certec och Professor Bodil Jönsson - från medicin till teknik. Min bakgrund som ekonom gör mig till en ovanlig och ibland främmande fågel i dessa världar samtidigt som jag finner mig väl tillrätta med det åtgärdsinriktade. Bodils intresse för mina livserfarenheter och förmåga att förvandla dem till vetenskaplighet har lärt mig mycket. Jag är tacksam för det.

Innehållsförteckning

Artiklar

I	Societal services after traumatic spinal cord injury in Sweden
II	Ethics in the making
III	On the need of validating inpatient databases

Sammanfattning

Licentiatuppsatsen baserar sig på tre artiklar. Arbetet syftar till att synliggöra och analysera hur samhällsresurser i praktiken görs tillgängliga (eller inte tillgängliga) och används (eller inte används) av en grupp traumatiskt ryggmärgsskadade individer.

Den första artikeln inventerar samhälleligt stöd och service som är möjligt att söka efter en traumatisk ryggmärgsskada. Ett 25-tal stöd identifierades vilka hanteras av i huvudsak 2 olika huvudmän/aktörer, kommun och försäkringskassa. Frustration uttrycks bland brukare över denna organisation samt att känna sig kontrollerad och ifrågasatt.

Den andra artikeln analyserar hur generella etiska riktlinjer utmanas av situerad etik i designsammanhang. Motsvarigheten här är hur intentioner bakom samhällsresursers tillhandahållande utmanas av upplevelser hos den berörda vad gäller bemötande, grad av komplexitet och möjligheten att genomskåda systemen och förutse deras effekter.

Den tredje artikeln behandlar slutenvårdsanvändning för den berörda gruppen och användbarheten av dessa data för att kartlägga gruppens totala användning. Vid en validering av detta register framkom att gruppens totala slutenvårdsanvändning ej gick att fastslå.

Artiklarna diskuterar även metodologiska aspekter på kartläggningen och dokumentationen av samhällsresurserna.

Syfte

Det sammanhållande syftet för föreliggande arbete är att *synliggöra* och *analysera* komplexiteten i samhällsresursers tillhandahållande. Organisationen studeras både utifrån vilka samhällsaktörer som existerar och hur dessa är internt organiserade, och vad det leder till för användning och icke-användning vid traumatiska ryggmärgsskador i ett livslångt perspektiv. Komplexiteten berör:

- Individen och hennes möjligheter att ansöka om och erhålla samhällsresurser. Analysen inkluderar etiska perspektiv och hur det tidsbundna i samhällets syn på funktionsnedsättningar påverkar resurstillgångar och resurstilldelning.
- Metodologiska aspekter på kartläggning av samhällsresurser.
- Hur samhällsresursers användande dokumenteras eller inte dokumenteras och hur detta påverkar underlag för framtida resursplanering.

Inledning

Prevalensen (totalantalet) personer med traumatisk ryggmärgsskada i Stockholmsregionen uppgick i början på 90-talet till 223/1 000 000 [1]. Dahlberg m fl rapporterar för Helsingfors-regionen en prevalens om 280/1 000 000 [2] medan incidensen (antalet nyskadade per år) i Nederländerna i början av 90-talet beräknades till 10,4/1 000 000 [3]. En traumatisk ryggmärgsskada medför ofta betydande förlust av motorik och sensorik och flertalet blir rullstolsburna [4]. Skadan är idag inte botbar och innebär i regel allvarliga komplikationer. Överlevnadsfrekvensen för personer som drabbats av en traumatisk ryggmärgsskada har ökat drastiskt sedan andra världskriget. Medellivslängden närmar sig normalbefolkningens och det finns idag skadade personer i hela ålderstrappan.

Att leva med ett omfattande funktionshinder innebär stora ansträngningar och kräver förändringar och anpassningar i den levda miljön. Handlingsalternativen begränsas, marginalerna blir mindre och konsekvenserna av oförutsedda skeenden blir större. I syfte att möjliggöra samhällelig integration, skapa oberoende, kompensera funktionsnedsättning och underlätta den dagliga livsföringen kommer den skadade under sin livstid att ha en stor förbrukning av vård-, stöd- och serviceresurser i samhället. Skadans komplexitet och påverkan på de kroppsliga funktionerna gör behoven stora. Vårdanvändning i både sluten och öppen form utgör en stor kostnadsandel men också andra resursbehov kan bli omfattande genom att i ett livsperspektiv vara repetitiva.

En skadad persons resursförbrukning belastar idag olika huvudmän: landsting, kommun, stat/försäkringskassa, försäkringsbolag och stiftelser. Stöd och service delas ut efter ansökan. Inga resurser tillhandahålls automatiskt efter en ryggmärgsskada. Varje resurs kan beviljas efter behovsprövning baserad på en skriftlig ansökan och intyg från läkare, kurator, arbetsterapeut och/eller sjukgymnast. I litteratur och i samhällsdebatten uttrycker ofta brukare frustration över sitt beroende av myndigheterna [5]. Frustrationen beror bland annat på dåligt bemötande, att man känner sig och sina behov ifrågasatta samt tidsutdräkt och bristande resurser hos myndigheten [6,7].

För en person med en omfattande och livslång skada kommer kontakterna med olika myndigheter/instanser att fortgå hela livet. Figur 1 illustrerar det kontaktnät som helt eller delvis kommer att etableras. Strukturen kan se olika ut för olika regioner i landet, typiskt är att varje enhet är organiserad efter ärendeslag där olika handläggare hanterar dem. För den enskilde personen innebär detta att många olika handläggare är och kommer att bli involverade i alla olika ansökningsprocesser.

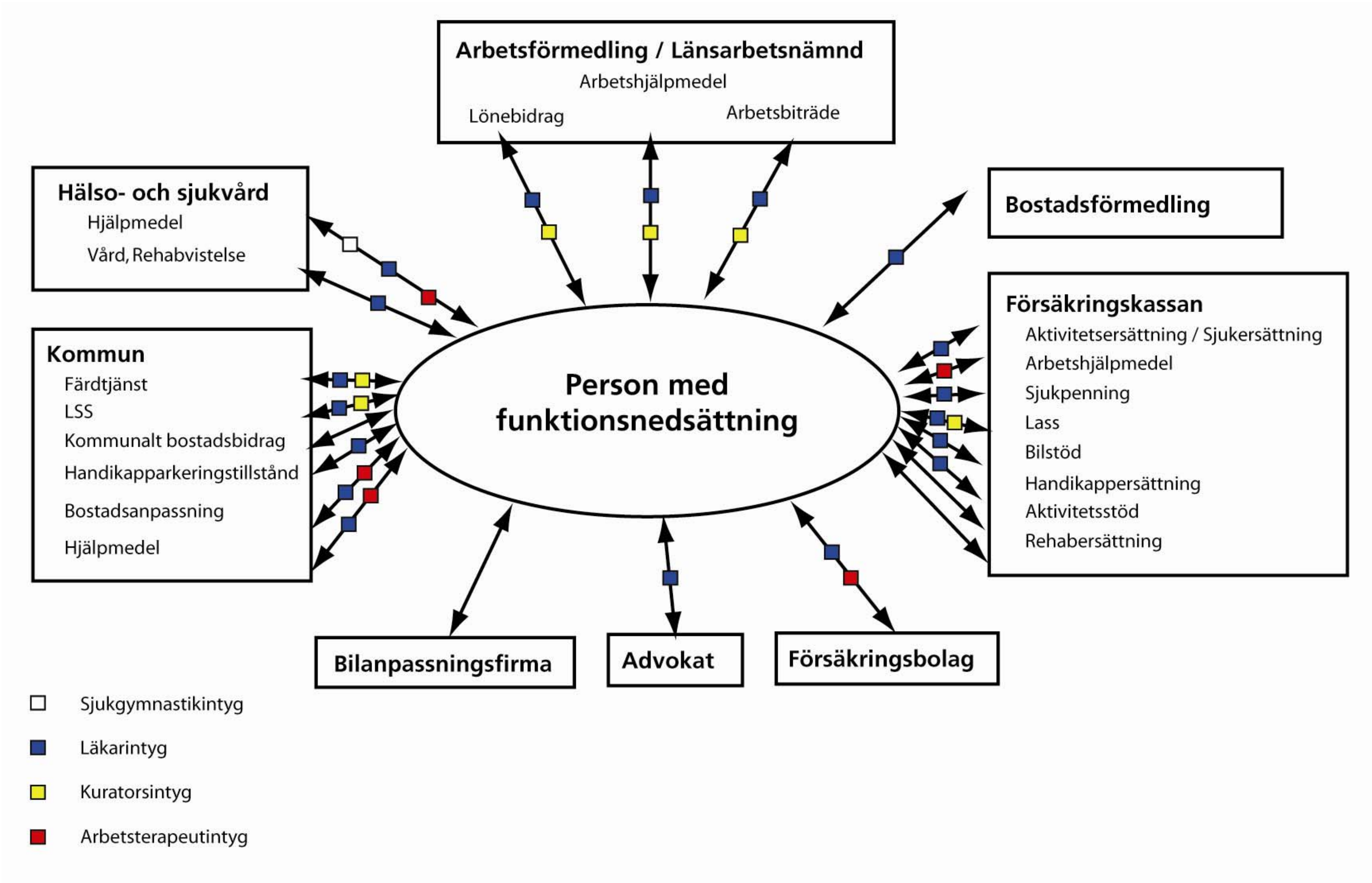

Fig 1. Möjligt samhällskontaktnät för personer med komplexa behov

Betydelse av diagnosrelaterade samhällsekonomiska studier

Kunskaper om resursanvändning och kostnader till följd av sjukdom/skada är ett viktigt underlag vid planering och prioritering av forskning, prevention, vård och rehabilitering [8]. Dock saknas många gånger uppgifter om både de direkta och indirekta kostnaderna. Ekonomiska konsekvenser vid kroniska tillstånd är svåra att studera eftersom resursutnyttjandet sker under en lång tid hos ett antal olika aktörer som vare sig ekonomiskt eller verksamhetsmässigt har samsynta och samordnade organisationer. Därför vet man också anmärkningsvärt lite om de totala effekterna av de samlade stöden [9].

Den ekonomiska vetenskapen utgår från att resurserna är ändliga och därigenom begränsade medan däremot behoven konstant tycks öka. Obalansen leder till att resurserna måste fördelas, så rättvist och så effektivt som möjligt. Hälsoekonomi söker den optimala lösningen för användandet av resurser inom hälso- och sjukvården [10]. Den ekonomiska utmaningen ligger i att välja bland möjliga alternativ så att man får ut så mycket hälsa och välfärd som möjligt av resursanvändningen. Studier av ekonomiska konsekvenser efter sjukdom/skada har på senare tid rönt större intresse och anses nu som en självklar del i offentliga policydokument. Dessutom ingår de i den medicinska och vetenskapliga samt populärvetenskapliga litteraturen [11].

Cost of illness - sjukdomskostnad

Det finns olika metoder för att beskriva ekonomiska konsekvenser av sjukdomar och olika interventioner (insatser). Studier som syftar till att beskriva den ekonomiska bördan av en sjukdom/skada för samhället använder metoden ”Cost of illness” (COI) [12]. En rad metodologiska avvägningar är förknippade med angreppssättet. COI kan baseras på incidens eller prevalens av en sjukdom/skada [13]. I studier baserade på prevalens beräknas samtliga kostnader för en geografiskt avgränsad population under en begränsad tid, vanligtvis ett år. I incidensbaserade studier däremot beräknas livstidskostnaden för en individ, från det att sjukdomen debuterar till dess att individen är botad eller avlider. Dessa studier kan vara svåra att utföra då kroniska tillstånd sträcker sig över decennier och därför begränsas ofta studietiden till ett visst antal år [11,12].

Kostnader identifieras på tre nivåer:

- Direkta kostnader, såsom vård- och läkemedelskostnader
- Indirekta kostnader, såsom produktionsbortfall till följd av t ex sjukskrivning, förtidspensionering och för tidigt dödsfall
- Abstrakta kostnader, såsom psykosociala kostnader

Det är önskvärt att alla kostnader inkluderas oavsett vilken huvudman eller organisation som bär kostnaden [11]. Uppgifter för att genomföra kostnadsberäkningar kan inhämtas genom register eller databaser (top-down) alternativt via enkäter, patientjournaler eller longitudinella studier av ett urval personer (bottom-up).

Kostnadsberäkningar sker i tre steg:

1. Identifikation av använda resurser
2. Kvantifiering av dessa resurser
3. Prissättning av resurser

Grunddata

En första svårighet att beräkna sjukdomars eller skadors sammanlagda kostnadsbörda ligger i att identifiera individer med ifrågavarande diagnos. Oftast sker det via utsökningar på diagnoskod. Man bör då ta ställning till huruvida den utsökta gruppen är en sann diagnosgrupp, d v s validera diagnossättningen samt om gruppen är total eller representativ. I föreliggande arbete föreligger inte denna svårighet. En numera reguljär öppenvårdsenhet med ett totalansvar för bl a samtliga traumatiskt ryggmärgsskadade inom Stockholms läns landsting, Spinalis, genomförde under början av 90-talet en inventering av personer med en traumatisk ryggmärgsskada inom upptagningsområdet. Då identifierades 379 individer [14]. Därefter har varje nytillkommet fall införts i Spinalis patientdatabas vilket varit möjligt tack vare en etablerad och väl sammanhållen vårdkedja. Databasens totalpopulation är unik i sitt slag. Andra länder har oftast bara tillgång till patientuppgifter utifrån en viss sjukhusanläggning eller ett visst försäkringssystem.

Forskning och publikationer

Föreliggande licentiatuppsats bygger på tre vetenskapliga artiklar:

I. Societal services after traumatic spinal cord injury in Sweden.
Camilla Nordgren, Richard Levi, Gunnar Ljunggren, Åke Seiger
J Rehabil Med 2003; 35:121-126

I detta arbete används intervjuer av 34 personer med traumatisk ryggmärgsskada för att identifiera de 25 olika samhällsresurser (utöver vård) som år 1998 var aktuella strax efter att en skada inträffat. Tillfredsställelsegraden med ansökningsprocedur och resursallokering skattas också.

Varje individ hade i genomsnitt ansökt om 5 resurser (0-11) under ett år. För 13 av de befintliga resurserna angav minst en individ att han/hon inte kände till att resursen var möjlig att ansöka om. Det fanns en stark frustration över systemet och många enskilda besvikelser, bl.a. över otillräcklig information och bristande koordination.

II. Ethics in the making.
Bodil Jönsson, Peter Anderberg, Eva Flodin, Lone Malmborg, Camilla Nordgren, Arne Svensk
Design Philosophy Papers, no 4, 2005

Denna artikel berör hur värderingar finns med inte bara i vad som görs utan också i hur det görs. Artikeln behandlar väsentligen design och teknik men motsvarande resonemang gäller också för samhällsresurser. Inte bara totalsumman spelar roll utan viktigt för den berörda är också bemötandet, graden av komplexitet, förutsägbarheten i systemen och möjligheten att genomskåda de samma. Generella etiska riktlinjer utmanas alltså av situerad etik. Vare sig ”the medical model” med sin inriktning på individuella funktionsnedsättningar och insatser eller ”the social model” med sin inriktning på ideologisk och politisk analys ger i sig tillräckligt fast mark för etiska ställningstaganden med hänsyn till den berördas upplevelser. Det är i stället hela *kedjan* av design och teknik respektive hela *kedjan* av samhällsresurser i sitt använda sammanhang som är det relevanta och utslagsgivande för det upplevt etiska.

III. On the need of validating in-patient databases.
Camilla Nordgren
Submitted to: European Journal of Epidemiology, 2006-04-07

Här studeras validiteten hos en befintlig nationell slutenvårdsdatabas (omfattande 495 personer med traumatisk ryggmärgsskada). Olika relevanta frågeställningar identifieras för att avgöra materialets användbarhet och för att möjliggöra korrektioner av vissa systematiska fel. Den initiala vårdepisoden visade sig korrelera med skadedatum endast för 62%. För resterande 38% låg första registrering mellan 2 och 8651 dagar efter skadedatum. Underlaget visade sig alltså ej vara komplett på denna punkt. Vidare hade vissa individer omotiverat korta vårdtider och alla rehabiliteringskliniker fanns inte ens med i registreringen. Åtminstone 5 väl kända saknas, medan 42 olika sjukhus och 47 olika kliniker, ingår i statistiken. Sammantaget visar studier att det krävs omfattande kunskaper om diagnosgruppen och dess slutenvårdsanvändning för granskning av data innan de kommer till användning. Utan en sådan granskning kan exempelvis prospektiva slutsatser bli direkt missvisande.

Material och Metod

Föreliggande arbete tar sin utgångspunkt i en rad individer drabbade av en traumatisk ryggmärgsskada. Ett flertal källor har använts i detta arbete;

- Spinalis öppenvårdsdatabas, Stockholms läns landsting
- Intervjuer med en incidensgrupp
- Informationsmaterial från försäkringskassa, kommun, arbetsförmedling, länsarbetsnämnd, försäkringsbolag och stiftelser
- Folkbokföringsregistret
- Patientregistret, Socialstyrelsen

Från Spinalis inhämtades uppgifter om personnummer, skadedatum, skadenivå och skadeomfattning samt skadeorsak för en incidensgrupp (Studie I). Under året 1997 och 1998 hade 48 personer ådragit sig en traumatisk ryggmärgsskada. 34 av dessa intervjuades med stöd av ett frågeformulär. Bortfallet om 14 personer berodde på dödsfall (2), avböjde intervju (2), kognitiva svårigheter (3) eller oanträffbarhet (7).

Också prevalensgruppen (Studie III), cirka 500 personer, hämtades ur Spinalis databas. I kvalitetssyfte genomfördes kontroller av gruppen dels om personen hade avlidit, dels aktuell mantalsskrivningsort och dels genom diagnosverifiering av verksam läkare på Spinalis. Mantalsskrivningsorten förutsattes vara väsentlig då det ponerades att om personen inte var mantalsskriven i den undersökta regionen använde denna inte heller vård inom regionen. År 2002 genomfördes en kontroll i Folkbokföringsregistret resulterande i 31 individer skrivna på annan plats både inom och utom landet. Om individen hade flyttat in och ut ur regionen kunde dock inte spåras.

Prevalensgruppens slutenvårdsanvändning över tid studerades med hjälp av uppgifter från Socialstyrelsens Patientregister [15]. I bearbetningen av detta material uppmärksammades en rad oväntade data. En rad hypoteser ställdes upp som sedan prövades genom registergranskning i gruppen om 495 personer (Studie III).

Etiskt tillstånd

För studie I uppfattar Karolinska Institutets regionala forskningsetikkommitté projektet som kvalitetsuppföljning varför den faller utanför forskningsetiska kommitténs arbetsområde. För studie III har etiskt tillstånd erhållits.

Resultat

Komplexiteten i samhällsresursernas organisation tydliggörs i figur 1.

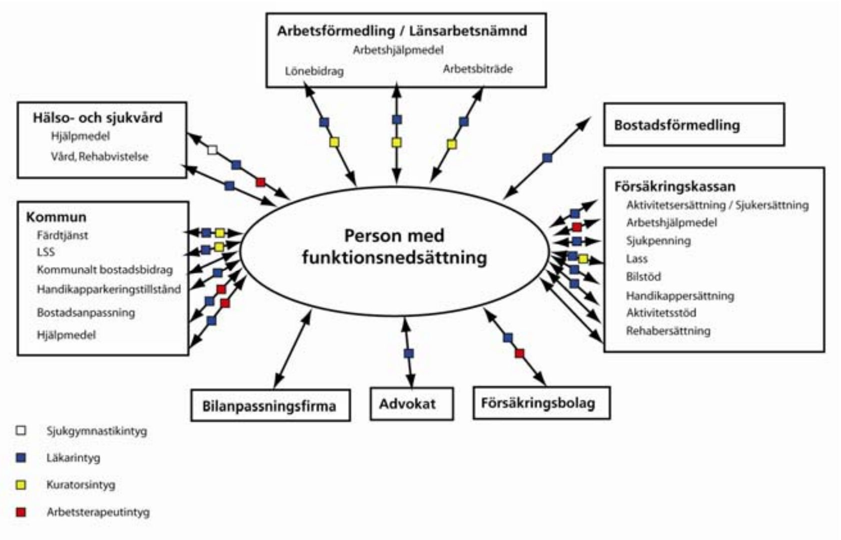

Fig 1. Möjligt samhällskontaktnät för personer med komplexa behov

Ett flertal huvudmän är aktuella varav tre är dominerande, landsting/region, försäkringskassa och kommun. Den stora mängden av olika slag av stöd/service illustreras också. Det förekommer att benämningen på stöd ändras, t ex blev förtidspension och sjukbidrag ersatt med aktivitets- och sjukersättning under 2003. Organisation, mängd och benämning av stöd/service samt ovana att ha dessa myndighetskontakter är samtliga faktorer som påverkar den upplevda tillgängligheten till stöden.

Att ansöka om och erhålla samhällsresurser

I Sverige finns en mängd stöd/service och vård allokerat för personer som har behov. Studie I visar emellertid att antalet stöd och deras organisering är svåröverskådliga och förorsakar mycket bekymmer för de berörda individerna. Någon strukturerad och formaliserad information om alla stöd finns inte, utan information ges vid förfrågan. Samtidigt som stöden är komplexa är individerna ofta oerfarna i att hantera blanketter och att förstå kanslisvenskan. Kuratorn på sjukhuset eller rehabiliteringsanläggningen visar sig ha en central roll för information om stöd och hjälp med ansökningar. Dock uppger ett flertal intervjuade att de inte kände till vissa stöd vilket visar att överföring av kunskap om stöd och service är sårbar. För ett antal stöd resulterar handläggningen i avslag, helt eller delvis. Detta gäller främst stöden handikappersättning och bilanpassning.

Informanterna ombads skatta tillfredsställelsegraden med själva ansökningsprocessen respektive utfallet av densamma. Överlag var individerna mera nöjda med utfallet än med handläggningen av ärendena.

Metodologiska aspekter på kartläggning av samhällsresurser

En incidensgrupp med förvärvad skada under 1997 eller 1998 intervjuades med stöd av ett frågeformulär. Istället för att fråga vilka resurser man hade ansökt om under ett visst år, räknades alla tänkbara resurser upp för intervjupersonen för att säkerställa att informanten inte glömde bort att ange något stöd. Svarsalternativen på frågan ”Har Du under 1998 ansökt om ….?” var:

- Ja

- Nej, varför ej?
  - a) Kände ej till stödet
  - b) Behövde ej stödet under 1998
  - c) Hade redan stödet
  - d) Annat

Genom att intervjua en hel incidensgrupp och inte enbart individer som erhöll ett visst stöd kartlades motivet till att en resurs inte uppbars.

Genom data från Socialstyrelsens Patientregister granskades prevalensgruppens slutenvårdsanvändning över tid. Registret i den undersökta regionen är komplett fr o m 1972 och de som skadats tidigare (58) uteslöts. Utifrån tre formulerade frågeställningar kunde konstateras att gruppens totala slutenvårdsanvändning ej gick att fastslå via Patientregistret. Det är uppenbart att registret först måste valideras, åtminstone utifrån de tre viktiga kriterier som det här arbetet ringade in (första vårdtillfälle i förhållande till skadetillfälle, vårdtiders längd och att alla kliniker skall omfattas) för att kunna användas.

Samhällsresursers dokumentation

Något samlat register för att på individnivå utsöka användning av samhällsresurser existerar inte. Data måste därför samlas in via primärkällor (individen) eller via de isolerade register som finns. Stor kännedom om vilka samhällsresurser som kan vara aktuella krävs för att genomföra och erhålla en komplett insamling. Kvaliteten på och relevans av insamlade data eller tillhandahållna register bör alltid granskas. Studie III beskriver risken med att använda ett register utan att validera innehållet. Konsekvensen av att dra slutsatser om att diagnosgruppens användning av slutenvård är lika med registrets innehåll leder till en stor underskattning av det totala vårdutnyttjandet denna grupp står för.

Diskussion

Föreliggande licentiatuppsats behandlar komplexiteten i samhällsresursers organisation och individers användning respektive icke-användning av vård, stöd och service i ett livslångt perspektiv. Arbetet tar sin utgångspunkt i individer med en traumatisk ryggmärgsskada. Syftet och angreppssättet lämpar sig dock även för andra livslånga sjukdomar/skador som medför funktionshinder och som kännetecknas av liknande komplexitet. Det komplexa samhällssystemet i kombination med den komplexa skadepåverkan medför stora svårigheter när använda samhällsresurser i ett livsperspektiv ska beskrivas.

Två omfattande studier av resurser och ekonomiska konsekvenser efter traumatiska ryggmärgsskador är gjorda av Berkowitz m fl [16,17]. Den första har sin tyngdpunkt på att bestämma prevalensen i USA och använder metoden COI för att sammanställa de totala sjukdomskostnaderna. Närmare 800 personer valdes ut genom ett slumpvis urval och intervjuades. Slutenvårdsanvändning kartlades de första två åren efter skadetillfället samt inom ett år före intervjun. Andra direkta kostnader som definierades var användning av läkare och paramedicinsk personal, läkemedel, personlig assistans, hjälpmedel och bostadsanpassning. Det konstateras att stora variationer förekommer i den initiala slutenvårdsanvändningen vilka inte alla går att förklara utifrån omfattning och nivå på skadan. Uppgifterna om slutenvårdstider kommer från intervjupersonerna varav 25% var skadade före 1970. Ingen diskussion förs om tillförlitligheten av svaren eller rimligheten i slutenvårdsuppgifterna. I den andra studien telefonintervjuades 500 personer som varit listade på sjukhus tillhörande ”the Spinal Cord Model Systems” samt personer som är medlemmar i ”Paralyzed Veterans of America”. Såväl direkta som indirekta kostnader undersöktes med fokus speciellt på bostads- och bilanpassning samt rullstolar.

Ingen heltäckande undersökning har gjorts i Sverige kring diagnosgruppen och använda resurser. Enstaka stöd har undersökts, t ex Levi m fl [18,19], som genom instrumentet ”Undersökning av Levnadsförhållanden”, ULF, Statistiska centralbyrån hos en population om 326 personer i Stockholm beskriver användning av läkemedel och förtidspension/sjukbidrag.

Att studera och kartlägga användning av samhällsresurser kräver att analysen genomförs och framställs i ett tidssammanhang. Lagstiftningen på handikappområdet har utvecklats från institutionstänkande till integration i samhället. När Lagen om stöd och service till vissa funktionshindrade, LSS, (1993:387) kom betonades individens rätt att använda samhällets stöd efter egna behov och val av livsstil [20] (även Lagen om assistansersättning, LASS, 1993:389). Individens funktionsoförmåga är bara en av de faktorer som styr resursbehoven och användningen. Bengt Lindqvist uttrycker i Bemötandeutredningen att enskildas värderingar och förväntningar om vad man har rätt till påverkar bemötandet. Det gör också handläggarens arbetsförhållanden, otydliga och komplicerade regelsystem som ofta ändras, brist på resurser och värderingsförändringar [21]. Andra exempel på påverkande utveckling och förändrat synsätt är sjukhus- och egenvård och dess effektivitet, teknik, politik, resurstillgång och omvärldens inställning till personer med funktionshinder. Ett exempel på en politisk åtgärd är förtidspensionering som var ämnad ges till individer som p g a medicinska skäl har en nedsatt arbetsförmåga men som under åren 1972 till 1990 också gavs av rena arbetsmarknadsskäl [22]. Ett exempel på bristande resurstillgång är bilstödet som de senaste åren har tagit slut före årets utgång. Sökande får då avvakta ett nytt budgetår.

Studie I och III beskriver faktisk användning i populationen. Huruvida denna motsvarar individernas behov av vård, stöd och service går inte att uttala sig om. Viktigt är emellertid att betona att behov och användning inte alltid är detsamma. Studie I ger en viss fingervisning om att användningen kanske kunde ha varit högre om den gruppen som angav att de inte kände till ett visst stöd faktiskt hade utnyttjat möjligheten att ansöka och erhålla stöd. Jonsson m fl skriver att mängden stöd från olika aktörer/myndigheter/organisationer gör det svårt för individer att påverka vilka slags stöd och service som går att söka och erhålla [9].

Att mäta och kartlägga använda resurser är komplicerat för ett omfattande livslångt och komplext tillstånd. Så som tidigare har beskrivits är en rad olika huvudmän involverade och stöden är många. Eftersom tillståndet är livslångt, många är unga då de förvärvar sin skada [14] och den förväntade livslängden är normal, kommer individen under lång tid att söka och erhålla olika stöd. Stöden kommer att variera beroende på behov och livssituation. De är i regel tidsbegränsade och måste sökas om, t ex handikapparkeringstillstånd. För bilstöd måste 7 år förflyta innan man är kvalificerad att söka igen. Andra stöd kan man ansöka om när behov föreligger men ibland föreligger oklarhet om hur många gånger man kan erhålla det, t ex bostadsanpassning.

Trots det unika Patientregistret visade det sig att även slutenvårdsanvändning var komplicerad att kartlägga. Figur 2 åskådliggör det flertal källor som måste beaktas för att kunna fastställa den totala slutenvårdsanvändningen hos en prevalensgrupp. Antalet personer som använt vård och omfattningen av densamma går ej att kartlägga utifrån tillgängligt material i föreliggande studier.

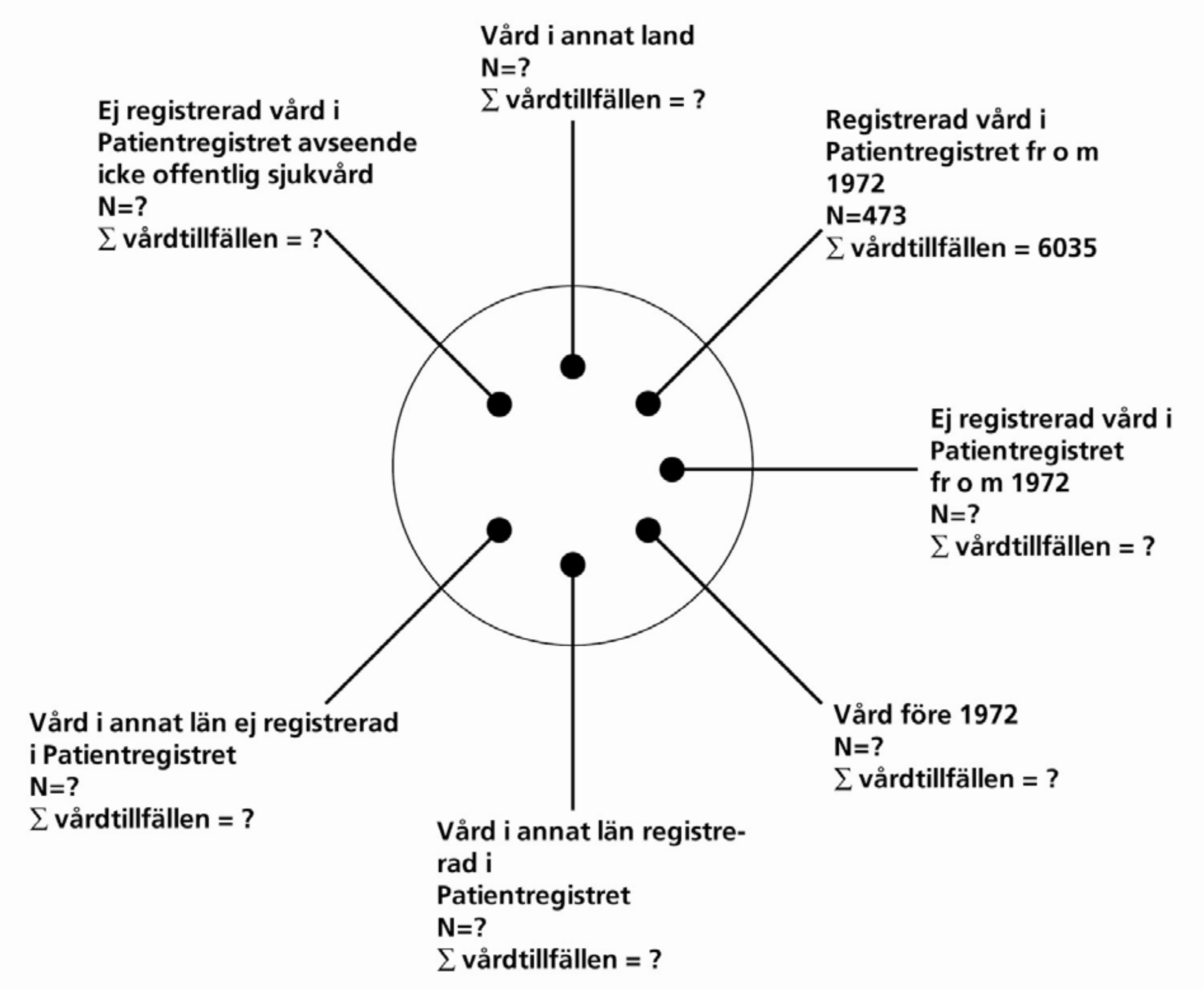

Fig 2. Källor för fastställande av total slutenvårdsanvändning för en prevalensgrupp (n=489) t o m år 2002

Det finns idag ingen kunskap om hur individualiserade resursbehoven är. Om t ex graden av resursanvändning korrelerar med skadans nivå och omfattning är osäkert. Studie I visar dock att personer med lumbal skada hade flest ansökningar.

Slutsatser

Studierna visar att Sverige har en mängd stöd/serviceresurser tillgängliga att ansöka om för personer med en traumatisk ryggmärgsskada. Organisationen av stöden och stödens mångfald gör tillgängligheten komplicerad. Viktigt för den berörda är bemötandet, graden av komplexitet, förutsägbarheten i systemen och möjligheten att genomskåda de samma. Generella etiska riktlinjer utmanas av situerad etik. Det är hela kedjan av samhällsresurser i sitt sammanhang som är det relevanta och utslagsgivande för det upplevt etiska.

Det går inte att kartlägga totalt använda samhällsresurser för den undersökta gruppen eftersom uppgifter inte finns tillgängliga på individnivå. Intervju av en grupp individer med avseende på stöd och service har därför genomförts. För slutenvård finns hos Socialstyrelsen ett Patientregister att tillgå. Dessvärre visar en validering av detta register att data ej är kompletta varför gruppens totala slutenvårdsanvändning inte går att fastslå.

Fortsatt arbete

I syfte att vidare kartlägga sjukdomsrelaterade resursanvändning enligt metoden COI kommer slutenvårds- och öppenvårdstillfällen för en prevalensgrupp samt service- och stödanvändandet för ett representativt urval i en prevalensgrupp traumatiskt ryggmärgsskadade att ske.

Användningsprofilen kommer att undersökas genom att analysera

- var i en livscykel resursbehovet uppkommer
- varför behovet uppstår
- om korrelation föreligger mellan resurs- och stödutnyttjande och personkaraktäristika
- spridningen av resursanvändning hos personerna
- vilken huvudman som belastas av kostnaderna

Vidare planeras att identifiera och jämföra en grupp förtidspensionerade traumatiskt ryggmärgsskadade personers resursbehov med inte förtidspensionerade skadade personer.

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SOCIETAL SERVICES AFTER TRAUMATIC SPINAL CORD INJURY IN SWEDEN

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Objective: **Societal services after traumatic spinal cord injury in Sweden were investigated, including self-rated levels of satisfaction with the application process and resource allocation.**

Design: **Survey of an incidence population.**

Subjects: **Thirty-four persons of a total regional incidence population ($n = 48$) with traumatic spinal cord injury.**

Methods: **Structured interviews using a standardized questionnaire.**

Results: **About 25 separate services were identified being available for persons with traumatic spinal cord injury. The average number of applications per person was 5 (range 0–11). The most common service was "transportation service". Of the applications, 17% were partially or totally rejected. Most subjects received information about available services from a social worker. For 13 available services at least 1 subject claimed ignorance about its existence.**

Conclusions: **In Sweden, significant resources are allocated for allowing independence and financial compensation for individuals with traumatic spinal cord injury. However, this support system sometimes also results in frustration and disappointment. Insufficient information and co-ordination are reported as weaknesses. The persons' efforts to acquire knowledge of how the system works take time which could be better used for rehabilitation and full integration into the community.**

Key words: traumatic spinal cord injury, societal services, consumer satisfaction, application process, resource allocation.

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INTRODUCTION

A spinal cord injury (SCI) may have devastating consequences for the person affected and commonly leads to significant, permanent disability. The need for societal services is thus obvious and an extensive and life-long reliance upon such services will typically be established. In order to restore social integration, re-establish autonomy, compensate for functional losses and facilitate activities of daily living (ADL), society provides various supportive services. Legislation regulates service availability by prioritizing those most in need. Services are administrated by several separate authorities, each with different organizations, objectives and cultures.

In Sweden, in addition to resources of a medical and rehabilitative nature, there are approximately 25 separate societal services potentially available for persons with SCI (Table I). Some of these services are mutually exclusive, but most are not and have to be applied for separately. In most cases, services are administrated by at least 2 different authorities, e.g. the regional social insurance office and the municipality. The employer and/or the Employability Assessment Institute may also be involved.

The population with SCI, however, often expresses dissatisfaction with this quite complicated system for service allocation (1, 2). Knowledge of the nature of this dissatisfaction is essential and its causes must be determined, described, analysed and fully understood in order to counteract it.

The relevance of factors such as demographics, injury characteristics and social support for community reintegration has been focused in earlier studies, e.g. by Whiteneck et al. (3). The issue of societal services, however, has not been closely investigated.

An SCI involves costs that are carried to varying degrees by the person involved, his/her social network and society, respectively. The most evident and easily identifiable cost is that of initial hospitalization. Several authors (4–7) have estimated initial and subsequent life-long direct and indirect costs. Berkowitz et al. (4) and Walsh (6) found, *inter alia*, that the costs of initial hospitalization constitute only a minor part of the total SCI cost. Since the services provided by society in most cases are iterative and life-long, they will represent a large part of the total costs.

A first step towards service allocation is an application. Each service has to be applied for separately by the applicants themselves. In most cases certificates from a doctor, social worker and/or occupational therapist are required in order to corroborate the person's conditions and/or application. The case is then processed and decided upon at the regional office and the applicant is notified of the decision. The decision can be appealed against.

Little is known about how the applicant experiences this process. The widespread use of patient satisfaction measures has not yet, to our knowledge, been applied in this field. Both the application process and its outcome are of relevance in this context.

The purpose of this study was to identify the spectrum of

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Table I. *Societal services and criteria for allocation*

Service	Criteria for allocation
Disability pension	Chronic illness or disablement and therefore inability to work
Temporary disability pension	Reduced working capacity for a limited period
Sickness allowance	Illness and therefore inability to work
Disability allowance	Need for time-consuming help from somebody in order to manage daily living, job or studies or substantial additional costs
Training allowance	Taking part in a labour market programme
Rehabilitation allowance	Undergoing rehabilitative treatment with a view to restoring employability
Wage supplement	Employing a person with reduced work capacity (a subsidy for the wage disbursed to the employer)
Assistant (while at work)	Letting an employed person at the working place help a disabled person with simple duties (a subsidy for the wage disbursed to the employer)
Technical aids	Need of technical aid due to the disablement at the working place
Work adaptation	Need of adaptation due to the disablement at the working place
Priority to an apartment	Social or medical reason for prioritizing in a housing queue
Housing allowance	Additional costs for the rent due to the disablement
Home adaptation	Need of adaptation in the home due to the disablement
Car allowance	Difficulties in transporting oneself or using public transportation
Car adaptation	Need of adaptation due to the disablement
Parking card	Difficulties in walking (permit parking on special places)
Transportation service	Difficulties using public transportation within the community
National transportation service	Difficulties using public transportation within the nation
Attendance allowance	Severe disability and necessity of personal assistance with basic needs, i.e. personal hygiene, dressing/undressing, eating, communicating with others, in daily living situations
Home help (service)	Need of help with, e.g. cleaning, laundry, providing meals
Home nursing service	Need of help with, e.g. changing bandage, medication
Escort service	Need of assistance while performing recreational activities

potentially relevant societal services early after SCI and analyse user satisfaction with the application process and resource allocation.

METHODS

In the years 1997 and 1998, 48 persons in the Greater Stockholm area and on the island of Gotland, Sweden sustained a traumatic SCI. The study group comprised 34 (71%) of these individuals. Fourteen persons were unable to participate in the study, out of which 2 had died, 2 declined, 3 suffered from cognitive limitations and 7 could not be reached. With regard to gender, age at injury and level of lesion, no differences were found between the study group and the excluded group.

Demographic data were obtained from the Stockholm SCI database (8). This database is a medical record system, which was adapted and implemented in the early 1990s as an instrument for structuring investigations, data storage and processing of patients with SCI. Descriptive data for the study group as regards level and completeness of lesion, according to the American Spinal Injury Association (ASIA) (9), are depicted in Table II. The group comprised 11 women and 23 men. Mean age at injury was 47 years (range 15–76, SD 17, median 48 years).

The criteria for being eligible for resource allocation, such as income, expenses, age or extent of disability were not investigated. It is therefore not possible to exclude any individual. The purpose of this study was to investigate an incidence group in order to illustrate the actual situation.

A questionnaire was constructed for the interviews, which were performed by one of the authors (CN) who had no connection with any of the authorities nor any professional contact with the social workers. The interviews took place between November 1999 and February 2000 and lasted between 20 minutes and 2 hours. The time was dependent on the number of services that were applied for and the complexity of the processing. The questionnaire comprised 2 parts. The first surveyed which services the persons had or had not applied for during 1998. The second focused on the application process as such and to what extent the resulting service allocation was in accordance with what was applied for and on the level of satisfaction with regard to administrative handling.

Whenever a person had not applied for a service, 3 possible reasons were identified: (i) the person was already receiving the service; (ii) the person did not claim to need the service in 1998; or (iii) the person did not know about the service.

Questions about the application process included information about available services, request for certificates, contact with the administrating authority, level of resource allocation, degree of satisfaction, information about the possibility of appealing and time from decision to delivery. The degree of satisfaction with resource allocation was assessed on a 4-point self-rating scale (1, not at all; 2, to a limited extent; 3, to a large extent; and 4, completely). A 7-point self-rating scale was used in order to measure the degree of satisfaction with the administration of the application (1, worst ever; 2, very bad; 3, bad; 4, pretty good; 5, good; 6, very good; and 7, best ever).

RESULTS

The study group applied for 175 services during 1998, with a range of 0–11 and an approximate average of 5 applications per person. No significant difference in the average number of

Table II. *Neurological classification*

Neurological level of lesion	Total *n*	%	Complete[a] *n*	Incomplete[b] *n*
Cervical	18	53	2	16
Thoracic	3	9	0	3
Lumbar	7	21	0	7
No level[c]	6	17	0	0
Total	34	100	2	26

[a] American Spinal Injury Association (ASIA) A; [b] ASIA B-D; [c] No residual sensorimotor deficit that makes it possible to identify the original lesion, ASIA E.

Table III. *Number of applications during 1998 vs level of lesion*

	Level of lesion			
Number of applications	Cervical *n* = 18	Thoracic *n* = 3	Lumbar *n* = 7	No level *n* = 6
0	2	0	0	0
1	1	0	0	2
2	1	0	0	0
3	3	1	1	0
4	1	0	0	4
5	2	0	0	0
6	0	1	2	0
7	3	0	0	0
8	0	1	2	0
9	1	0	0	0
10	4	0	1	0
11	0	0	1	0

applications could be found between women and men. The number of applications in relation to level of lesion is illustrated in Table III. Persons with lumbar injuries showed the highest number of applications per person and persons with no level, the lowest.

Category of service

Table IV shows the distribution of applications for the different services. The most common service applied for was "transportation service" ($n = 31$) followed by "home adaptation" ($n = 17$) and "sickness allowance" ($n = 16$). Ten persons answered that they did not know about the "disability allowance" service and 7 did not know about the "national transportation service". None had applied for "wage supplement" or "assistant (while at work)".

Handling and outcome

The subjects were asked to rate their degree of satisfaction with the administrative routines, including the attitudes and behaviour of the authority representatives, the time interval from submission of the application to decision, the quality and extent of pertinent information and the resource allocation. Table IV depicts the results of the maximal ratings of these questions. For the services "car allowance" and "car adaptation" only 1 person out of 11, and 1 out of 9, respectively rated the handling as "Best ever" or "Very good". Generally, subjects were more satisfied with outcomes than with the handling process as such.

Information about the service

One piece of information extracted from the questionnaire was that the vast majority of the study group was informed about available services by a social worker at the hospital or rehabilitation clinic. The social worker typically handled the

Table IV. *Distribution of service applications 1998 and ratings of handling and outcome by category (*n = 34)

Service by category	Yes *n*	Handling[a] Best ever and Very good *n*	Outcome[b] Completely and To a large extent *n*	Already receiving 1998 *n*	Did not need 1998 *n*	Did not know about the service *n*
Income support						
Disability pension	3	2	2	4	25	2
Temporary disability pension	6	5	4	1	26	1
Sickness allowance	16	7	14	0	17	1
Disability allowance	13	6	7	0	11	10
Work						
Training allowance	1	1	1	0	29	4
Rehabilitation allowance	7	4	6	0	27	0
Wage supplement	0	0	0	0	34	0
Assistant (while at work)	0	0	0	0	34	0
Technical aids	7	6	7	0	27	0
Work adaptation	1	1	1	0	33	0
Accommodation						
Priority to an apartment	8	8	8	0	25	1
Housing allowance	8	6	6	0	24	2
Home adaptation	17	7	12	1	16	0
Transportation						
Car allowance	11	1	9	0	20	3
Car adaptation	9	1	5	0	23	2
Parking card	14	13	13	0	18	2
Transportation service	31	29	30	1	2	0
National transportation service	5	5	4	0	22	7
Attendance						
Attendance allowance	6	3	5	0	27	1
Home help (service)	9	6	7	0	24	1
Home nursing service	2	2	2	0	32	0
Escort service	1	1	1	0	33	0

[a] Ratings possible: Best ever, Very good, Good, Pretty good, Bad, Very bad, Worst ever; [b] Ratings possible: Completely, To a large extent, To a limited extent, Not at all.

application and requested doctors' certificates as well. For some services, such as "parking card" and "transportation service", the social worker was typically in charge of the whole application process and the outcome for the person with SCI was a letter containing the "parking card" or licence for "transportation service". For other services, the social worker assisted initially in the application process, whereas subsequent phases of the process involved direct contact between the representative of the relevant authority and the person in need.

Resource allocation

An application being made is no guarantee of a service being granted. The outcome of an application for services is either provision of the service or partial or total rejection. A "car adaptation" application can, for example, be partially rejected when all adaptations applied for are not granted. The authority representative has then made a judgement that the applicant does not fulfil the criteria for the allocation. Table V gives an overview of partially or totally rejected applications in the study group. Seven persons (out of 13) received a partial or total rejection of an application for "disability allowance". The corresponding figure for "car adaptation" was 7 (out of 9).

Three narratives

In order to illustrate inter-individual variations as well as intra-individual complexity of the administrative handling process, narratives of 3 plausible cases are presented.

Case 1

Bill sustained his C5, ASIA B injury in a motorcycle accident at the age of 30 years. He was a gym trainer at the time of injury, he lived with his wife in a single-storey house. She contacted the social insurance office soon after the accident to arrange for "sickness allowance". Bill felt too sick to participate at that time. His wife reported that the administrator seemed to lack insight into Bill's predicament and was unhelpful. Bill felt the administrator to be ignorant about his situation. However, the allowance was provided immediately and Bill rated his satisfaction with the handling as 5 and the outcome as the maximum 4.

Table V. *Partially or totally rejected applications. Number and percent of total number of applications for each respective service*

	Applications	
Service	No. rejected	% of all
Disability allowance	7	54
Priority to an apartment	1	12
Housing allowance	2	25
Home adaptation	4	24
Car allowance	3	27
Car adaptation	7	78
Parking card	1	7
Attendance allowance	2	33
Home help (service)	2	22

The hospital social worker informed Bill about "disability allowance", to be handled by another administrator than the one handling "sickness allowance". Bill provided much the same information again and this duplication in reporting was further emphasized by the involvement of 2 or 3 additional administrators. The handling of the application, however, did not take long and Bill rated it as 5 and the outcome as 4.

The hospital social worker also informed them about "home adaptation". Bill's wife helped him to contact the municipal department. Its administrator failed to grasp what needed to be done and why in spite of drawings being provided. When 2 weeks remained of his 5-month in-patient stay at the hospital no adaptation had yet been carried out. When Bill called attention to the cost of additional in-patient care, things started to happen. Bill rated the handling as 1 and the outcome as 4.

Bill also became aware through the social worker of the possibility of applying for a "car allowance" and "car adaptation". Bill found the administrator at the social insurance office unable to understand the importance of an accessible car. Bill and a car dealer therefore had problems filling out the forms properly. Then funds were temporarily low and the allowance was transferred with a delay. Bill rated the handling as 1, the outcome of the "car allowance" as 3 and the "car adaptation" as 1 since he did not get all the required adaptations. The social worker also helped Bill apply for a "parking card", which he received immediately. The handling and the outcome were both rated maximally.

Bill applied for "personal assistance" after information from the social worker at the rehabilitation clinic. The administrator showed little sympathy for the requested amount of assistance. However, Bill was content with the outcome and rated it as 4. The handling was also rated as 4.

Case 2

Karl sustained his L3, ASIA B SCI when he fell from a tree, while picking cherries at the age of 50 years. Being a teacher Karl contacted the social insurance office about the "sickness allowance", which was administrated immediately and he rated the outcome as 4 and the handling as 7. The administrator of the "sickness allowance" informed him of the "disability allowance" and the administrator who dealt with this. Karl found a need to exaggerate his functional disability rather than showing rehabilitation results. The allowance was less than applied for and did not cover his extra costs, so he rated the outcome as 1. The handling was rated as 3.

The social worker and the occupational therapist at the hospital informed him about "home adaptation". Karl applied to the municipal administrator but was not granted all the adaptations he considered necessary. He rated the outcome as 2 and the handling as 6. Karl decided to obtain all the adaptations anyway and thus paid for some of them himself.

The social worker at the rehabilitation clinic informed him about "car allowance" and "car adaptation". Additional information was provided by a company dealing with car adaptations. Karl was completely satisfied with the outcome of the "car allowance", but rated the outcome of the "car adaptation" as 2 since his application was partly rejected. Karl rated the handling for the allowance and the adaptation as 4. Karl also applied for a "parking card". He was informed by the social worker and the card arrived within 2 weeks. The outcome and handling were both rated maximally.

Case 3

Anna sustained a C5, ASIA C injury at the age of 45 years when her bicycle collided with a car. She was married and the mother of 3 children. Anna's husband and the hospital social worker helped her to make contact with the social insurance office to apply for "sickness allowance". Later Anna also applied for a "rehabilitation allowance". She rated the outcome as 4, while the handling was affected by insufficient information and rated as 4.

The hospital social worker helped Anna to apply for a "disability allowance" through the social insurance office. The application was approved and the payment arrived immediately. Anna rated the outcome as 4 and the handling as 6. The social worker also handled the "home adaptation" application. The adaptations were performed without delay and Anna rated the outcome as 4 and the handling as 7.

The rehabilitation clinic informed her about "car allowance". The outcome was satisfactory and was rated as 4. However, the information was delayed and the handling was therefore rated as 5. Anna was also told at the clinic about "car adaptations" and experienced the lack of comprehensive information assembled in one place. The formal application was made by telephone and the outcome was rated as 3. The handling was also rated as 3. On Anna's behalf the social worker applied for a "parking card", which Anna received by post. The outcome was rated as a maximum 4 and the handling as 6.

The hospital social worker dealt with the application for "personal assistance". The outcome was rated as 4. However, the implementation was late and the handling was therefore rated as 4.

DISCUSSION

The present study reflects that several societal resources are available to individuals with SCI in Sweden soon after the injury. Only a few of these resources are utilized by the majority of the SCI study group.

There is no formal, structured information provided by society about services available to individuals who have sustained a disability. The authorities provide information on request. None of the above-mentioned services are placed at the SCI person's disposal automatically; every service requires some kind of application. Social workers at the hospitals or rehabilitation clinics typically arrange help for persons with SCI. The fact that a number of the study group individuals did not know about particular services indicates that this routine is vulnerable. This suggests that services that the persons are entitled to may not be granted, due to poor information, or because the social worker judges that the applicant does not fulfil the criteria for the service to be granted. This result shows the importance of examining a total prevalence group in order to determine the experiences not only of persons who are "in the system".

Many subjects indicated that they did not need the service in 1998. One interpretation is that they did not consider the service necessary in compensating for the disability. Another is that they did not require the service in 1998 (but maybe did later on). A third interpretation is that the individual with SCI was already receiving another service, mutually exclusive to the one required. Still another interpretation is that the family was providing the service. The fact that the degree of service depends mainly on income, expenses, age or extent of disability, may explain why some persons do not apply for the service. They are aware of this regulation and know that they are not eligible. Such individuals also answered that they did not need the service in 1998. It should be emphasized that it is not possible to determine the total need of services for the study group by considering only the granted services, since regulations and/or insufficient information exclude some persons with needs.

Persons with lumbar injuries made the highest number of applications. Comparisons between level of lesion on one hand and quality of life and medical problems on the other have been reported earlier, see, for example, Westgren & Levi (10) and Levi et al. (11). Since many services are provided in order to compensate for the disability, one might assume that those with higher injuries, and thus more extensive impairments, would also have had more need of services and consequently applied for more. It is not possible in this study to establish a statistically significant correlation between the number of applications for services and the level of lesion, but the result is still worth noting.

The study population more frequently reported partial or total rejection of their applications for the services "disability allowance" and "car adaptation". One explanation for this may be a significant component of subjective judgement on the part of administrative staff based on indistinct legislation. The reported number of rejections was only for formal applications. Since many intended written applications start with a telephone contact with an administrator, this may result in verbal discouragement. Such inhibiting effects are difficult to estimate, both in number and impact on the life of the person affected.

Living with an SCI poses several obstacles in daily life. Overcoming these is time consuming. For the affected individual with the intention of living fully integrated in society with work, family and leisure activities, time thus becomes a problem, i.e. the impairment leads to less time being available. For most individuals with new SCI, contacts with and knowledge of the social welfare system are new experiences. There is a complicated system of rules, which is often dependent on the budgeted resources. The necessity of acquiring knowledge of this system demands effort and time. In most cases the social worker assists the individual, resulting in a more effective handling. As most services have a time limit and must be applied for iteratively, the disabled individual typically has to re-apply without continued support from the social worker. Post et al. (12) showed in a study from the Netherlands that a majority of respondents rated satisfaction with service delivery procedures as low, especially factors such as attitude, number of organizations and officials involved and the amount of time required for these procedures.

If the person with SCI unequivocally fulfils certain criteria for receiving the service an application may be considered as a "reservation". This is valid for such services as "parking cards" and "sickness allowances". From the SCI person's perspective, verification comes in the delivery of the card or payment in response to the application. For other services such as "home adaptation" and "disability allowance", the application is but a first step towards a further assessment of the needs. Such a procedure may require considerable time and patience. The difference between these 2 ways of handling an application may be confusing and misleading to the person in need. Keith (13) showed that research in healthcare generally demonstrates high levels of satisfaction and that dissatisfied patients tend to seek other providers. For a person in need of societal services, however, there are few if any alternatives. This creates a double "lock-in", firstly because of the rules and judgements and secondly because there may be no other provider.

The questionnaire included an inquiry about handling time. Post et al. (12) found that discharges for one-third of the respondents from the rehabilitation centre in the Netherlands were delayed because residential adaptation was not completed, while the corresponding figure in Forrest & Gombas' study (14) was 10%. In our study one person reported a similar situation. A certain degree of adaptation of the home is often necessary before discharge. However, it is likely that further modifications will need to be carried out when the person with SCI has settled in.

An holistic approach to rehabilitation needs to include the entire process of returning to independent living. Today, different organizations are responsible for different parts of the rehabilitation and reintegration for SCI individuals. An initial period of hospitalization with the objective of minimizing the impact of the injury and optimizing the conditions for long-term survival with good quality of life must, however, be enhanced by the authorities responsible for services meeting the objective of rehabilitation for full community reintegration. If this enhancement does not succeed, many of the resources invested in the initial phase will not be as useful and effective as expected.

In conclusion, the social security system in Sweden has allocated significant resources for allowing independence and financial compensation for SCI-related impairments. The number of services available reflects this notion. However, this study shows that the present state of affairs often creates frustration and disappointment on the part of the disabled person. The complexity of the system is often reported as a shortcoming within the entire disability movement and not only within the SCI sphere. The problem is the same for all affected, but it might have greater impact for those persons acquiring a complex, life-long injury/sickness. In spite of the social worker's role as a co-ordinator between the authority and the person in need, insufficient information and co-ordination are reported as examples of weaknesses. In order to achieve a fully satisfactory system of societal services either the number of processes and authorities must be reduced, or an official co-ordinator must be appointed, with the explicit task of acting as a proxy for the person in need. The task must be determined without delay so that the person with SCI is given the opportunity to be properly supported throughout life.

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II

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ethics in the making

Bodil Jönsson, Peter Anderberg, Eva Flodin, Lone Malmborg, Camilla Nordgren & Arne Svensk

Applied ethics in research is no longer regarded as a concern exclusive to the medical field. Exemplars in ethics from other fields such as design are, however, meagre, as are relevant practical and design applied guidelines. The more ethically grounded a given area of research is, the greater the chance it can contribute to long-term, meaningful breakthroughs in knowledge. An improved *ethics in design* can enable a critical questioning that in turn leads to entirely new research questions.

The mere involvement of human subjects and the application of safety provisions in design research do not guarantee it will meet ethical considerations, best practices or standards. The entire complex interaction with users offers intriguing possibilities and risks, or can result in mediocrity in areas such as: preparation and implementation that is worth the research person's time; respect for users' contributions; dignified treatment; feedback in an iterative and interactive process with mutual information and inspiration; and products and processes that are truly influenced by the users. This reasoning applies to all, but with special distinction to people who are disabled and elderly. Starting with specific needs as opposed to more general ones (the latter of which result in the necessity for more abstract specifications for the multitudes) can, above and beyond the ethical dimension, also result in increased innovation and effectiveness for society on the whole. Proceeding from the particular to the general is of considerable value, for ethical reasons as well as for sheer effectiveness.

Involving persons with a variety of disabilities in product development helps to ensure innovative and useworthy products.[1] One of many prerequisites for ethically sound user involvement is that all participants are aware of the interference taking place in an iterative design process.

An elaboration of ethical aspects in design can be valuable for different stakeholders (user organisations, NGOs and the design community) and, of course, for the relevance of resulting products and processes. A more considerate ethical approach could have substantial economical value due to the higher relevance of the results. There has been a considerable increase in the ethical expectations placed on businesses and professions in recent years. Scores of organisations have reacted by developing ethical codes of conduct and professional guidelines to explicitly state their values and principles.[2] Moreover, the drafting of a code of ethics can be seen as an indication of professionalism in an emerging profession.[3]

Ethical guidelines versus situated ethics

Traditionally, medical research and clinically practicing professionals have been in the vanguard of creating ethical guidelines, with other research fields involving human subjects and human well-being close behind. Today, the medical disciplines are also front runners in combining their work on general ethical principles (autonomy, justice, and beneficence, for instance) with research on situated ethics, which is less mechanistic and closer to the context of real people in actual situations and work practices.

Situatedness urges different approaches for different disciplines. The engineering and design sciences, having safety, accessibility and 'universal design' of artefacts and the built environment on their agenda, cannot lean towards medical exemplars. They need to develop their own. An initial difficulty is that the existing key ethical principles, however 'universal' they appear to be, originate from medicine. The spirit of the *Nuremberg Code*, the *Helsinki Declaration* and *The European Convention* (with its explanatory report) is not particularly vitalised in design, to say the least.[4], [5], [6] The reason is obvious: none of them have been formulated based on experiences from design of civil products for everyday life. Nonetheless, ethical aspects are definitely present in test usages as well as in the influence of the resulting technology in later, everyday use.3 Ethical design perspectives can also be deduced from *The Charter of Fundamental Rights of the EU* ('the right to freedom of expression and information'), [7] the *Convention on the Rights of the Child*, [8] and from *Citizens Rights and New Technologies: A European Challenge* in which the European Group on Ethics in Science and Technologies (EGE) stresses the two basic concepts of *dignity* and *freedom.*[9] Accessibility and 'design for all' are such fundamental perspectives that they should not be treated separately. They have societal implications for education, information and participation in social and political processes. *The Principles of Universal Design*, with the approach that environments, services and products should be designed for use by as many people as possible regardless of situation or ability, is an example of this perspective.[10]

Creating common guidelines for rehabilitation design is a challenge, as is the possibility of working the other way round: to open up for a mainly *situated ethics,* based on the spirit of existing codes and declarations rather than being deduced from them. The core of situated design ethics is made up of means and methods that (using the main declarations as guidance) reveal the most important ethical aspects in a given situation, elaborate these, document the thoughts, their implementations and outcomes and make them openly available with the goal of yielding exemplars and inspiring a vital and on-going discussion.

Exemplar 1: You have to have options to make a choice

Hanna was born with a nerve-muscle disease that severely restricts her mobility. At 1½ years of age, she received her first standing support device in order to exercise her muscles and put pressure on her skeleton. In the process of standing, however, she discovered that there was a lot to see from this upright vantage point. Objects in other parts of the room caught her attention. Without the support of her mother's arms she was suddenly on her own in the world. She wanted to come closer to the objects that she could see at the edge of her upright horizon. Her mother had to move the stationary supporter to the thing that attracted Hanna's attention. 'There! There!' she said and pointed. She quickly focused on something else and wanted to move on to it and then the next object and the next. Her mother soon realised that this was not so much about Hanna's wish to interact with different objects: what she actually was after was the enjoyable feeling of moving around in an upright position. This resulted in the construction of a motorised standing support device that offered Hanna the opportunity to move around in an upright position on her own.

One such device after the other has seen the light of day and enabled Hanna, now a young adult, to gain the identity of a standing – not a sitting – person, including all the existential, physical and practical effects and side effects involved. One such side effect (that was foreseen) is that Hanna will never master the ability to sit – she will remain a standing or a lying person for the rest of her life. The critical moment is to be found in her early childhood when the people in her surroundings were open-minded enough to start questioning whether a future position as a seated person would be right for Hanna with her 'stand-up' ambitions.[11], [12]

This exemplar might serve as a revelation: what are the ethics (if any) behind the dominating 'wheel-chair-for-all' attitude that in no way questions the underlying assumption that somebody who cannot stand up and walk on her own has to live her life primarily as a seated person? In design terms: what are the ethical issues involved in not offering motorised standing supports as an option for mobility injured people? It is easy to understand that an aid in the best of cases does not only fulfil the function it is meant to (to stand up in the example of Hanna); it can also reshape the person's existence and existential terms (Hanna achieved an autonomous, upright mobility). This aspect should be involved in future body technology.[13]

In design, the focus might be on 'that-which-ought-to-be' (*desiderata*) versus 'that-which-is' (description and explanation).[14] The concept of *desiderata* is an inclusive whole of aesthetics, ethics and reason. *Desiderata* is about what we intend the world to be, which is more or less the voice of design. The greater the difference between the designer's and the user's worlds of concepts, the greater is the need for a user-adjoining and situated design process. You need to immerse yourself in concrete experiences – not only base your understanding on abstract ones. You need to accept and acknowledge the existence of different communities of practice.[15] You need to accept desire as an initiator of change. You need to allow disturbances and not only inform and be informed, but also inspire and be inspired. Designers may be informed and inspired by the users, at the same time as the users are informed and inspired by the designers. Utilising this two-way information and inspiration in both groups to its full extent has profound ethical implications, while at the same time making the process more efficient and situated. Cf. the framework by Kensing and Munk-Madsen.[16]

Cultural probes

Among situated design methods, cultural probes have a special position and they have developed in two primary directions: the inspirational and informational. The pioneer version of cultural probes belongs to the first direction. It was developed at the Royal College of Art, Computer Related Design by Bill Gaver and focuses on novel forms of self-reporting by participants on details of their everyday lives. These are then taken up to inspire the design process. The group of academic and artistic members were working on redesigning three community sites in Norway, Holland and Italy. The idea behind these probes was to provoke inspirational responses from elderly people living at the sites.[17], [18], [19]

The informational direction of cultural probes developed out of the design research community oriented towards use of ethnographical methods in the design process. Pioneers in this usage of cultural probes have been members of the Cooperative Systems Engineering Group, Computing Department, Lancaster University in the UK, which has extensive experience in the use of ethnography in design.[20]

We believe that the "friction" contained in the probe's design also works as a way of inspiring users to create new use situations and to look at their environment in a new way – with new glasses.

In interactive design processes involving people with extensive language limitations, questionnaires and interviews are extremely blunt instruments for capturing people's dreams, needs or aversions. Cultural probes are many times preferable in this context because they do not require specific prerequisite knowledge or language abilities. We introduced a number of probes in a day activity centre for people with cognitive and communicative limitations. The reactions to these cultural probes have both inspired and surprised us.[21]

Example: Cultural probes as a source of inspiration

One probe was a web camera for communication. During the initial connection, the sound disappeared so the researcher and day activity centre participant could only see one another on their respective computer screens moving their lips. The researcher quickly telephoned the person at the day activity centre (the phones were next to the computers) and on the screen the two of them could see each other sitting there holding the telephone receivers to their ears and talking. From the facial expression of the person at the centre, it was obvious that this was a true “Aha!” experience. It took a while before the researcher realised that the surprise was because this was the first time the person in question had actually seen what it was like for the person at the other end of the line. Since then, the two take turns phoning one another even though the sound works on the computer because the feedback the user receives from using the telephone and from seeing the person he is talking to doing the same, provides him with more clues to the mystery of telephoning.

Design ethics and the human sector

> To smash the little atom,
> All mankind was intent.
> Now every day,
> The atom may
> Return the compliment.
>
> Max Born, Physicist, Nobel Prize Winner, 1882-1970

State-of-the-art in design ethics has been well elaborated in another issue of *Design Philosophy Papers*, particularly in the articles by Donahue and Fry.[22], [23] Addressing ethics makes it possible to discuss what design does, what it contributes and what designers may affect in their work. As Tonkinwise puts it, ethics has always been associated with human-to-human relations.[24] But, according to Latour, artefacts are society and culture made sustainable.[25] Products, artefacts, built environments and communication are also ‘actants’ themselves and therefore enter the ethical domain not only as neutral means used by humans in their relations to other humans. Using an analogy from physics, Bruno Latour finds in designed activities what he labels ‘the missing masses’, which is to say that if we only take into account what we currently understand by ‘sociality’, our cultures should have long since collapsed into irretrievable immorality. The ‘missing masses’ names an ethical force hidden beyond what we now call ‘the social’, and the force is in the things per se. Things are acculturating or ethos-generating and a vital part of any ethos with a future.

In the *human sector* people work with and for other people. In addition to healthcare, schools and social services, this sector comprises people-to-people operations in business, the rest of society and the large, informal sector/economy in which people help people because they are relatives or friends. Awareness of the role of artefacts and design of new artefacts requires design processes that proceed from the *logic of the human sector*, not the technical one as is the case in the electronic, manufacturing and forest industries. With another approach to humans in design, the opportunities for real participation of people with disabilities increase, as do their opportunities to make decisions on their own.

The design of a new technology can have a strong impact on the human sector and help improve it.

Exemplar 2: Being there

The following excerpts from Peter Anderberg’s study elaborate how people who have significant mobility/physical impairments *and* who are accustomed to using computers experience the internet:

For the individual, the bodiless presence on the internet has many advantages. Why waste energy trying to convince your banking establishment to rebuild its entrance, when internet banking is so much easier? Why risk the danger of being dragged up the stairs to the local pub when it is so much easier to go to an online forum for company, where you do not have to worry about physical safety, accessible restrooms or deal with the attitudes of others? This ease and convenience, however, can easily lead to self-imposed restrictions, where what is experienced as choice becomes a restraint instead. The choice is very understandable on the individual level, but for the political endeavours of disabled people as a group, the picture becomes somewhat more complicated. The invisibility of the body can undermine the understanding of how disability is created in society, and be used against the community of disabled people. Why should a university adapt its buildings when most classes are available as online and distance studies?

> There was a sense that the world was moving in their direction, with increasingly more societal functions being moved to the internet. An online identity is becoming a more 'normal' one for all. If everybody else finds their information or does their banking over the internet, *being there* is the most important. [[26]]

This exemplar not only illustrates the influence of design and technology on human individuals and groups/mankind as a whole but also pinpoints some reflections with special significance for the human sector. If a successful innovation system is to be achieved in the human sector, it should be based on how people live and act rather than how machines function. A methodology can be initiated that deals not so much with 'running faster' but with 'running differently' and with a clear sense of purpose.[14]

Design science in relation to other sciences

Our intention here is not to elaborate this relationship generally but restrict ourselves to perspectives from the field of disabilities and the natural sciences. By doing so we hope to add new dimensions to the ethical discourse.

Human needs, wishes and dreams are the starting points for design research in rehabilitation engineering. The design of technical solutions represents in itself an interpretation of problems in a language of its own, different from the word-based analyses of observations, interviews, questionnaires and the like.

A design process in a disability context has to start with the person, end with the person and interact with her throughout the process if the results are to have any success. The situated is a necessary but not sufficient condition. It is a matter of understanding the action in its context and having previous scientific knowledge and considerable, solid experience in order to see the structures and possibilities and from that, propose solutions. The solutions that grow out of the situated processes represent in themselves an interpretation of the actual problem and illuminate them in an implemented form and in their own 'languages', based less on words and interpretation and more on that we humans, in action, can show one another what we mean. This was already pinpointed and analysed by Vygotsky in the 1930s.[27] Paul Dourish discerns similar perspectives from a phenomenological interactive design perspective.[28]

Exemplar 3: Pictures as a language

Sometimes virtual reality can be experienced as more real than actual reality. This can only be revealed through artefacts. For some people with autism, communication with other people isn't sufficient, not even that which includes pointing at the real object. It may require a detour by means of artefacts so that the concrete can be made real for the person involved. During an outing in the woods, a special education teacher placed her hand on a stone at the same time as she asked a pupil with autism to sit on it. The pupil did not seem to understand at all what she meant. She then took a photo of the stone with a digital camera and showed the display screen to the pupil while at the same time asking him to sit down on the stone. He did so immediately.[29]

Case studies compared to statistically based studies

Case studies should not be considered merely pathfinders for later statistically based studies.[30] They have significant advantages that cannot be found in statistical studies and vice versa. The field of rehabilitation engineering and design is based largely on case studies. This is not only because of the difficulties in finding enough subjects in the same 'category'; it is also (mainly) connected to the situated: it is the human being in her environment together with those around her that is the focal point. To pretend that one's own everyday environment can be replaced by a laboratory environment without considerably influencing usability tests is not only naïve but unethical in its approach.

Exemplar 4:

When designing a friendly restroom for elderly or disabled persons, interactions with the future users play an important role. To replace authentic users with young people loaded with weights and knee-joint movement restrictors reveals a misunderstanding of the situation as well as an absence of respect. Our experience tells us that research persons from the actual groups are happy to commit their time, share experiences and take part in testing. But it is pointless not to take into account outside influencing factors such as how much sleep the person got the night before, time of the day, season, increased or decreased weight, temperature, etc. Average percentages in usability tests that disregard the influences of these factors are misleading and of much less importance than relevant situated descriptions of individual cases and processes out of which later important patterns of needs and wishes can be detected.

Most often, the design of doors, locks, alarms, toilet seats, lighting, etc. are carried out separately. For the target groups, the margins are so small that a failure in one can result in a failure of all that follows – it is the entire chain of artefacts and the complete process that ought to be tested. The key question is whether the research person is satisfied with the situation and can carry out the desired activity without too great an effort even if one of the tasks negatively affects what follows.

Design and action research versus phenomenology and grounded theory

In rehabilitation engineering and design, the researcher is supposed to lean forward rather than lean backward, to be a practitioner but a reflective one.[31] Although seldom mentioned or brought up to a conscious level, technology and design involve action research. Action research is sometimes considered questionable in social sciences. There is a fear that the researcher might be involved to such a degree that he or she is no longer 'objective', and that the situation is so biased that it can no longer be scientifically studied. However, *not* being an action researcher in rehabilitation engineering and design, *not* aiming to improve situations, solve problems, strengthen capabilities, enable functioning – at least in the long run – is unethical in the context discussed here.

The quality criteria of design in a disability context are linked to interaction with the user, through cultural probes, sketches, mock-ups, prototypes, material or immaterial artefacts; and observing and intervening in actual usage. It is possible to use emerging technology early in the design phase to reveal new knowledge about the user. Of course, a process of this kind influences the persons involved, but that is not to be considered a drawback. On the contrary, it is a built-in part of the process and a cornerstone of the research. It is part of the aim of the iterative design process. Including the user with the designer and researcher in the design process is 'a goal, not a foul.'

Let's take a look at two of the fundamental concepts in phenomenology: *phenomenon* and *lifeworld*. Phenomenon in this context does not stand for the occurrence in and of itself, but for the occurrence experienced by someone. The word 'phenomenon' means 'that which shows itself' and it is implicit in the definition that there is someone to whom it is shown. Our focus on the experienced person – the individual with the disability – thus becomes obvious from a phenomenological perspective. It is the phenomenon as it appears to her that we want to call attention to; how she experiences her world and the special conditions that we, if we understand them, can help to improve and enhance with an assistive aid. 'We want to go back to the things themselves,' says Edmund Husserl, phenomenology's founder, in his 1901 publication *Logische Untersuchungen*.[32]

The *lifeworld*, the lived world, is the other indispensable concept and is strongly associated with that of phenomenon. The lifeworld is the world we already find ourselves in, are familiar with and take for granted. It is pre-reflexive and pre-scientific and it both influences us and is influenced by us. We exist in this world with our bodies, which, in the philosophy of the French phenomenologist Maurice Merleau-Ponty, is an integrated whole that he calls 'the lived body'. 'The body is the vehicle of being in the world'. 'The body is the general medium for having a world'.[33]

Phenomenology's desire to allow phenomena, the things that appear, to be the controlling factors, in our opinion is close to Norman's affordance, a concept that surfaced 80 years later.[34] A significant difference is that phenomenology does not just indicate the phenomena, the individual things and how they emerge, but also the lifeworld as the point of departure. Affordance is a concept that originally was used in psychology to describe how objects, people, situations and so forth, offer or afford opportunities for possible interactions to an observer. It is these offerings in the first place that we perceive when we are confronted with phenomena.

The designer in a rehabilitation context has quite a different task than a researcher in a grounded theory context, where the task is mainly to understand what is happening and how the players manage their roles. The researcher gains understanding through observations, conversations and interviews. Data collection, note taking, coding and sorting are all part of the work before writing; categories and theories are supposed to emerge during the process. Grounded theory is distinguished in that it is explicitly emergent and does not test hypotheses. The aim, as Glaser explains, is to discover the theory implicit in the data.[35]

Design versus the medical or social model

Of course, there are many models in disability sciences, but none that is satisfactory for design. *The medical model* oversimplifies disability as an individual characteristic and directs awareness towards individual adjustments and means. *The social model*, on the other hand, directs awareness towards ideological and political analysis, not towards practical everyday solutions for experienced functioning. In 'Making both ends meet', Peter Anderberg introduces what might be the beginning of a relevant model, *FACE,* in which Function is analysed from three different factors: Attitude, Control and Enabling.[36] One of the advantages with the FACE model is that it necessitates the consideration of ethical aspects.

Design science and natural sciences

Regardless of theoretical or methodological standpoint, the only research result worthy of the name is new knowledge. Accordingly, in a research project it is seldom the entire process or the project results as such that are the actual research results; the new knowledge generated in the project often constitutes a rather minor portion. But it is essential to identify and define this knowledge and relate it to what already exists. This is quite a delicate task. It helps considerably if the methods involved are standard for the related scientific fields. However, this is not always possible. The phenomenology of Husserl's time as well as grounded theory and to some extent abduction mean that the phenomenon that is the object of investigation can and should be the controlling one.32 The disadvantages with inventing your own methods are manifest – much is required for the results to be considered credible. At the same time, the advantages are also manifest: it is through them that you achieve proximity to the reality being investigated. The researcher is forced to take more responsibility for the knowledge building than if he or she follows established methods.

Large areas of rehabilitation engineering and design can be dealt with within the framework of epistemology and can thus pride itself on:

- its ability to systematise and accumulate
- its ability to articulate new questions
- its openness and transparency even in its handling of methods and data
- its capacity to generalise on the basis of experience gained
- its openness to other perspectives which may make the results look different

In all these instances, epistemology strives for universality, context-independence and non-relativism. This is advantageous – *provided that it is possible and relevant*. If not, the priority of the particular must apply.[37]

To sum up

In rehabilitation engineering and design, there is a need for concrete experiences, acknowledgement of different communities of practice, acceptance of desire as an initiator of change, and an openness for the value of two-way inspiration and information. This all implies an ethics that is dual: operationally situated but with its exemplars continuously questioned and examined in the spirit of international ethical codes, charters and declarations. Induction, deduction, and abduction in between the generalised ethical level and the situated one would vitalise ethics in the design research community. The processes can be strongly facilitated if the confusion and overlaps of design concepts could be replaced by more standardised and agreed-upon core concepts.

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III

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On the need of validating inpatient databases

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Abstract

Health care utilisation is often analysed retrospectively in epidemiologic and health services research, aiming to yield a better evidence basis for the future. The validity of the vast amount of health care information collected in administrative databases cannot be taken for granted; validation has so far been neglected. This study reports a validation process of an inpatient database held by the Swedish National Board of Health and Welfare. This nationwide Hospital Discharge Register contains data from the early 1960s. An accurate diagnosis prevalence group (n=495) was acquired from the Swedish Spinalis Clinic. Their inpatient information was retrieved from the Hospital Discharge Register. Three main questions were raised to check the validity of the database and evaluate the amount of systematic error: Is an inpatient stay associated with the injury date? Is the reported first hospitalisation episode plausible given the level and extent of injury? Are all anticipated care and/or rehabilitation providers represented in the material? For 62% the first reported hospitalisation date correlated with the injury date. For the other 38%, hospitalisation was reported to start between 2 and 8651 days after injury. Considering the level and extent of injury, individuals were reported to have unrealistically short initial hospitalisation. The prevalence group visited 42 different hospitals and 47 clinics. Five rehabilitation clinics, though, were not reported. This study reveals comprehensive systematic errors resulting in an underestimation of inpatient care utilisation on incidence and prevalence levels. Extensive knowledge of the diagnosis group has been a necessity for examining and evaluating the data. Researchers using administrative databases should always validate their data to reveal possible systematic errors.

Key words: Administrative database, Hospitalisation, Inpatient care, LOS, Traumatic spinal cord injury, Validation process

Abbreviations

ASIA	American Spinal Injury Association
DRG	Diagnosis Related Group
HDR	Hospital Discharge Register
LOS	Length of stay
SCI	Spinal cord injury

Introduction

Describing and analysing people's utilisation of health care is indispensable for prognosticating future care utilisation and for conducting economic evaluations, epidemiologic studies, and clinical trials. In order to develop effective treatment programmes, understanding the nature and extent of health service utilisation is essential. Principally, there are three different ways to collect data: patient supplied, medical records or administrative databases. Several studies have been conducted evaluating the accuracy of the patient surveying method, e.g. [1, 2]. Both over- and under-reporting of hospitalisation episodes have been detected. Horwitz et al. [3] assessed the reliability of epidemiologic data from medical records and proposed strategies for improving the basic quality. Utilising administrative databases or secondary data involves analysis after collection without a specific research purpose and interference by the researcher [4].

In recent years, data retrieval has been facilitated by the vast amount of health care information collected and stored in databases and registers. Advantages of using these secondary sources are substantial time and cost savings, the size of the sample, the representativeness and the reduced likelihood of bias due to non-response [4]. Despite these advantages, this method has possible shortcomings that must be dealt with. Structural weaknesses and biases due to incomplete and inconsistent reporting and coding are mentioned. Furthermore, completeness, accuracy, validity and reliability are critical issues [5].

A common problem for many epidemiology researchers is whether the diagnosis code in question detects all true cases in these databases [6, 7]. Blomqvist [5] discusses three methodological approaches for assessing the completeness of registration of cases. The first is to compare the data source with several other independent data sources, the second is review of medical records and the third builds on a comparison between total numbers of cases in different sources. De Vet et al. [8] provide a theoretical background for performing and reading systematic reviews of diagnostic studies by discussing methodological quality in terms of internal and external validity. Rosen [9] argues that validation has been studied and reported. However, determining true cases is not enough. In analyses examining health care utilisation, e.g. cost-of-illness studies, the data must also be validated. Without such validation, the support for study results is poor and the prediction for future health care vague. This fact, however, is generally neglected and studies seem to lack descriptions of the validation process and its application to the data included.

In an international evaluation of Swedish public health research, it was concluded that Sweden is one of the world leaders in public health research including epidemiology and register-based research [10]. The use of the Hospital Discharge Register (HDR) has resulted in numerous research articles in different fields, e.g. [11-13].

This paper examines the inpatient care utilisation registered in the Swedish HDR [14] in an accurate diagnosis group: traumatic spinal cord injury (SCI). Whilst diagnosis detection is a problem for many researchers, this study has the advantage of having access to a population-based cohort of individuals with traumatic SCI.

Methods

Data sources

Spinalis is a comprehensive regional SCI outpatient clinic in the greater Stockholm area and the island of Gotland, comprising about 1.9 million inhabitants. A health care database was established in the beginning of the 1990s from a survey of regional registers and after individual patient contacts by the Spinalis rehab team. The dropout rate was 6.9% [15]. This procedure assured the accuracy of the database as an SCI health care database. Spinalis is a part of the established referral procedure, which insures further incidence inclusion in the database. In June 1999, the author submitted a retrieval request to this database with the inclusion criteria of living patients with traumatic spinal cord injury. The present study is based on the 495 persons who met these requirements. Data about birth dates, gender, injury date, level and extent of injury (ASIA) [16] and cause of injury were collected for each individual. In order to detect false positive and false negative cases, registers of individuals with other spinal cord injuries were investigated. These person's medical records were inspected for unreliable facts.

The HDR is complete in the investigated region from 1972. All cases with an earlier injury date were thus excluded (n=58). By checking the Swedish national registration office it was found that one person had died before June 1999 and was consequently excluded from this study. Ten persons were in inpatient care on the actual injury date or in direct connection with to it. Five of these were being treated for other reasons and in the meantime sustained a traumatic SCI. Another two persons did not have a traumatic SCI and were excluded. Three persons' injury dates were inaccurate and were corrected. The list of cases and their diagnosis was verified by a physician. This led to the exclusion of an additional four individuals who did not have a traumatic spinal cord injury. One person had an incorrect personal identity number and was therefore not included in the HDR investigation. One individual registered in the non-traumatic list was included after it was found that this person had a traumatic injury. This resulted in a prevalence group of *430 traumatic spinal cord injury cases (out of the originated 495).*

The Hospital Discharge Register: Statistics of diseases and surgical treatments of patients have a long history in Sweden. In the 1960s, the National Board of Health and Welfare started to collect data on individual patients who had been treated as inpatients at public hospitals. The county of Stockholm has since 1972 reported all inpatient care to the HDR [14]. There are different types of information in the register: data on the patient and hospital, administrative data such as date of admission and discharge, and medical data with diagnosis and surgical procedures. For all records reported to the HDR, data and quality controls are carried out.

The unique personal identity number assigned to each Swedish resident was used to obtain data from the HDR. Information about each person's registration regarding hospital/institution, clinic, unit, date of admission and discharge, type of visit, diagnosis, code and date for surgical operation and code for diagnosis related groups (DRG) were collected. Data was examined from 1972 through 2002.

Validation process

Validity is defined as whether the variables actually measure what was intended to be measured. The HDR consists of numerous individual pieces of information. Validating an extensive database thus requires investigations on an individual level. Understanding each person’s incentive and condition for utilising inpatient care requires knowledge about individual characteristics such as birth and death facts, residential registration, gender, injury date, level and extent of injury (ASIA), and cause of injury. Expectations were formulated as questions regarding what was to be found in the HDR. The first question put to the data was: Is an inpatient stay associated with the injury date? The second question was: Is the reported first hospitalisation episode (length of stay – LOS) plausible given the level and extent of injury? An episode is defined as the period from admission until discharge to something that does not lead to a registration in the HDR (i.e. being treated as an inpatient at a public hospital/institution). The third question was: Are all the anticipated care and/or rehabilitation providers represented in the material?

Ethics

This study was approved by the Ethics Committee of Karolinska Institutet in Stockholm, Sweden.

Results

Is an inpatient stay associated with the injury date?

For 22 individuals, day and/or month of injury was not specified in their medical records. For those individuals lacking an injury day, the first day in the month was calculated as the injury day. For those lacking an injury month and day, the first of January was specified as the injury day and month.

Table 1. Number of days between injury date and first registered inpatient stay

Table 1 shows the number of days between injury date and the first registered inpatient stay. Seventeen persons did not have any inpatient care at all reported after the injury date (three had registered inpatient care before the injury date; fourteen did not). Sixteen individuals actually had an inpatient stay registered the day before the actual injury. About 62% of the group had an inpatient stay reported in direct connection with the injury date (-1, 0, 1 days), i.e. 38% had their first stay 2 days or more after the injury date.

Is the reported first hospitalisation episode plausible given the level and extent of injury?

The number of inpatient days was checked for the individuals with a first hospitalisation stay in direct conjunction with the injury date. Included were those with a reported inpatient stay of –1, 0 and 1 day in relation to the injury date (n 257). Table 2 shows the distribution according to level and extent of injury and gives information of LOS for the initial hospitalisation.

Table 2. Length of stay in the first hospitalisation episode after injury date distributed according to level and extent of injury

It was noticed that an initial LOS for some individuals seemed to be interrupted by a holiday such as Christmas or New Year. For 20 individuals this was indeed the case. These inpatient stays had an interruption that lasted between 3-31 days, and by including these individuals' inpatient care after the interruption, the total stay was thus prolonged by 2-171 days.

Are all the anticipated care and/or rehabilitation providers represented in the material?

The inpatient stay prevalence group (n=413) had utilised care at 42 different hospitals/institutions in the Stockholm area, and 47 different clinics from injury date through 2002.

Discussion

This paper examines the validity of the content in an inpatient database. The use of a verified population-based health care database including additional controls ensures the validity of the diagnosis group investigated and the validity process can thus focus on the inpatient data. Considerable knowledge of the diagnosis and its effect in terms of health care utilisation proved to be a prerequisite when putting questions to the HDR. Interpreting data and estimating the validity was absolutely necessary for finding under-reporting and lack of reporting.

Extensive investigations were made regarding the patients included in the health care database, e.g. if and when a person had died and his/her residential registration were verified. Odd inpatient entries such as being admitted to inpatient stay and sustaining a traumatic SCI during that time were also examined.

Is an inpatient stay associated with the injury date?

A traumatic spinal cord injury is an acute and serious condition where immediate care is necessary. The alternative of not seeking care or waiting a couple of days occurs, if ever, in exceptional cases. Some studies analysing LOS, separate acute care hospitalisation from rehabilitation hospitalisation and stipulate a time limit from the injury date as an inclusion criterion [17-20]. Others calculate the LOS from the day of injury [21], include individuals admitted for their initial episode [22] or use date of the index hospitalisation as the date of the SCI [23]. All these studies lack further analysis regarding possible divergence between the onset of traumatic SCI and admission day. Putzke et al. [24] and Fine et al. [25], on the other hand, include individuals admitted on the first day of injury. In the present study more than one third of the prevalence group did not have an initial inpatient registration (-1, 0, +1 day) in conjunction with the injury date. The time lapse between injury date and first inpatient stay should be interpreted as possible days spent in inpatient care.

The prevalence population examined includes persons who have moved to the investigated region and who have a traumatic SCI sustained earlier. This group includes immigrants and residents moving from other parts of the country. The health care system in Sweden allows people to seek health care anywhere in the country. It is most common, however, to utilise the health care system in one’s own county. Since the patient data originated from one region, utilisation of care in other parts of the country was not included. In 2002, controls carried out at the Swedish national registration office resulted in finding 31 persons who were registered in a region other than Stockholm. Not being a resident of Stockholm in 2002 does not, however, say anything about place of registration at the time of injury. If a person had moved out of the area and then moved back into the area before April 2002, these movements could not be traced. One explanation for the high figure of divergence besides immigrants could be individuals injured during a temporary stay abroad or in another region in the country. These individuals are typically moved to their resident hospitals after the first trauma period and so, their initial hospitalisation would not have been recorded in the investigated database.

Is the reported first hospitalisation episode plausible given the level and extent of injury?

Quite a few studies examine factors impacting LOS: changes in management [26], severity of injury [22, 27, 28], respiratory complications [29], the incidence of pressure ulcers and neurologic improvement [30], occurrence of anaemia or hypoalbuminaemia [27], timing of spinal stabilisation [31], age at injury, sex, neurological level of lesion, Frankel grade, medical complications, associated injuries and surgical procedures [25], age at injury only [17, 20, 32], gunshot versus nongunshot SCI [24], decade of admission [33] and gender only [34]. All these investigated variables show different results. This study describes initial LOS according to extent of and neurological level. Table 2 presents a LOS range from 2-653 days, with a mean of 126 and median of 108 days.

Comparing results from other investigations is a way of determining whether the reported inpatient figures are plausible. A literature review on traumatic spinal cord injury and initial LOS shows a great variety in the number of days spent in hospital/rehabilitation with figures ranging from 1 up to 4742 days (Table 3). These studies all have different inclusion criteria, terms of description and grouping when it comes to etiology, age, injury year, level and extent of injury and type of care. This impedes comparison. No discussion has been found in any of the published studies about how realistic it is to have very few or many inpatient days registered. SCI patients at high risk of extended lengths of stay, referred to as outliers, are defined in a study of Burnett et al. [35] as patients whose lengths of stay exceed the mean length of stay by more than two standard deviations, while Cifu et al. [17] use four standard deviations. These studies discuss the outliers in terms of long LOS, but it should also be of considerable interest to focus on outliers in the other direction, in terms of short LOS.

Table 3 Literature review on initial length of stay

The present findings do not differentiate type of care: acute vs. rehabilitation. The data represent days of inpatient stay irrespective of type, in a public hospital. As seen in Table 3, some researchers do not examine the acute LOS. Several studies [18-20, 34] spring from persons discharged from the Model System with an enrol system of patients being admitted within 60 days of injury. In some studies, 86-93% of all patients are admitted to the investigated clinics within 21 days of injury. It is thereby uncertain how much inpatient time the patients have consumed before the rehabilitation LOS. It can therefore be interpreted that the LOS could in some cases actually be prolonged by as much as 60 days. A lack of differentiation between the acute and rehabilitation organisation could perhaps explain some of the differences and the great range of LOS.

Having a complete (ASIA A) cervical injury and utilising only 2, 7 or 22 inpatient days seems unrealistic. Revealing the likelihood of having an extremely short or long initial inpatient stay requires further investigation through other sources of data. Knowledge about medical care organisations in your country, rehabilitation regime and, of course, the investigated diagnosis are of value when determining which cases need more examination.

Are all the anticipated care and/or rehabilitation providers represented in the material?

The HDR administrated by the Swedish National Board of Health and Welfare contains inpatient data from public hospitals. Surprisingly, at least five institutions/rehabilitation units (Stora Sköndal, Stiftelsen Humlegården, Frösunda Center/Stockholm Rehab Station, Mälargården and Röda Korset) were not represented at all in the database. These institutions are typically foundations or privately owned. One of these, Frösunda Center/Stockholm Rehab Station, is included in the established referral procedure of rehabilitation and a great majority of all incidence patients stay at this rehabilitation unit for a while. Normally, the county council purchases care and rehabilitation services from these providers. Analysing the consequences of not including these rehabilitation units requires great effort since no computerised data on an individual level is accessible.

To investigate inpatient care in an administrative database presupposes that the disease in an individual has been reported and recorded in the system. Blomqvist [5] points out three factors that influence this: the care-seeking behaviour of the person, the supply of health care, and the physician’s propensity to admit patients. The nature of an SCI does not leave a person in doubt whether to seek care or not. Nor can the health care organisation in Sweden be seen as a hindrance to inclusion in the information system.

Low validity may imply systematic error. This occurred for two of the investigated factors in this study:

- Systematic exclusion of initial inpatient utilisation for individuals possibly not injured in the region
- Systematic exclusion of ‘not public’ hospitals/rehabilitation institutions

Systematic errors are not easy to discover and the chance of discerning them does not correlate with the size of the sample. When found, it is possible to compensate for them. The occurrence of non-systematic errors in this material could be due to errors in reported dates which were not detected by the validation process performed. Further investigations of each individual’s medical records must be carried out in order to detect them.

In conclusion, the HDR is a valuable source when conducting epidemiologic and health services research. However, using the HDR without any validation process could, as detected in the investigated diagnosis group, lead to a severe underestimation of the LOS in the region, both on incidence and prevalence levels. Quantifying the figures of this underestimation shows that almost 40% of the patients did not have an inpatient care episode in close connection to the injury date. Unrealistic figures regarding initial LOS were also found. Efforts made to judge the extent of these unrealistic figures by comparing reported LOS in different countries were complicated. This was due to different health care organisations and study inclusion criteria. At least 5 rehabilitation clinics were not represented in the material. This study reveals comprehensive systematic errors. Extensive knowledge of the investigated diagnosis group has been a necessity for examining and evaluating the data. Researchers using administrative databases like this one must always validate their data to attain reliable results.

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Table 1. Number of days between injury date and first registered inpatient stay

Number of days between injury date and first inpatient stay	Number of persons (N=413)
-1, 0 or 1	257
2-10	46
11-100	44
101-1000	22
1001-10000	44

Table 2. Length of stay in the first hospitalisation episode after injury date distributed according to level and extent of injury

Neurological level of lesion	ASIA A[a] (Complete)	
	n	LOS
Cervical	29	2,7,22,95,104,135,138,142,144,155,160,171,173,179,181,189,199,205,208,209,217,227,229,239,251,254,316,321,653
Thoracic	36	82,89,103,104,106,108,108,111,113,115,121,125,128,132,135,137,141,143,143,149,149,151,154,164,168,168,189,193,202,202,204,220,227,231,329,518
Lumbar	3	46,127,215
Sacral	2	62,217

Neurological level of lesion	ASIA B-D[a] (Incomplete)	
	n	LOS
Cervical	86	10,15,17,19,28,30,30,30,30,31,32,34,34,35,42,43,43,45,55,58,60,61,65,66,67,67,67,70,73,74,74,75,76,81,82,82,83,85,87,92,93,96,100,103,105,106,115,115,115,116,118,120,123,123,124,130,132,136,136,137,142,150,152,153,153,154,157,159,162,167,167,170,174,177,198,198,209,219,221,244,251,273,277,293,365,637
Thoracic	33	16,22,29,35,36,39,49,53,54,59,75,83,92,102,109,115,116,123,128,130,134,136,144,158,164,166,176,180,187,228,234,393,447
Lumbar	40	7,8,9,16,18,19,28,32,39,41,51,55,66,70,78,88,90,94,96,96,97,97,102,104,105,111,135,146,164,173,183,201,225,232,232,232,239,381,412,477
Sacral	2	19,111

	ASIA E[b]	
	n	LOS
	23	2,5,9,12,14,17,19,19,24,34,34,35,36,40,55,57,58,59,68,77,83,103,124

Neurological level of lesion	ASIA no information	
	n	LOS
Cervical	0	
Thoracic	1	290
Lumbar	1	381
Sacral	0	
No information	1	60

[a] American Spinal Injury Association (ASIA) [16]: [b] No residual sensorimotor deficit that makes it possible to identify the original lesion

Table 3. Literature review on initial length of stay

Author **Variables Investigated**	**Post et al. [36]**	**Eastwood et al. [18]**	**Samsa et al. [37]**	**Tooth et al. [22]**	**Cifu et al. [17]**
Year of investigation	2000-2003	1997	1970-1986	1993-1998	1988-1996
Number of patients	118	373	1250	167	375
Injury level	Tetraplegia, Paraplegia	Tetraplegia, Paraplegia	Quadriplegia, Paraplegia		C8 or higher
Injury extent		Incomplete, Complete	Incomplete, Complete		
ASIA	A, B, C, D				A, B, C, D
Frankel				A, B, C, D, E	
LOS Acute					
Mean		20			17.1[e], 20.8[f], 18.8[g]

±SD					±18.8[e], ±16.4[f], ±17.23[g]
Median					
Range					
LOS Rehabilitation					
Mean	274.8	60.8	300[a], 255[b], 218[c], 219[d]		70.8[e], 71.9[f], 72.4[g]
±SD	±150.0	±38.7	±183[a], ±222[b], ±244[c], ±119[d]		±53.4[e], ±44.2[f], ±49.3[g]
Median	243		263[a], 223[b], 182[c], 200[d]	206[a], 64.5[b], 96.5[c], 43.0[d]	
Range			1-1644[a], 1-2187[b], 2-4742[c], 3-692[d]		

[a]Tetraplegia, Frankel A, [b]Tetraplegia, Frankel B-E, [c]Paraplegia, Frankel A, [d]Paraplegia, Frankel B-E, [e]Age 18-34, [f]Age 35-64, [g]Age 65+

Author **Variables Investigated**	**Seel et al. [20]**	**Cifu et al. [32]**	**Greenwald et al. [34]**	**Ronen et al. [33]**	**Bravo et al. [38]**	**McKinley et al. [19]**
Year of investigation	1988-1998	1988-1996	1988-1998	1962-1992	1989-1991	1992-1999
Number of patients	180	2169	1074	250	123	87
Injury level	T1-L5	T1-L5	C1-L5	Cervical, Thoracic, Lumbosacral	T1-T4 excluded	C1-L5
Injury extent						
ASIA	A, B, C, D	A, B, C, D	A, B, C, D			A, B, C, D
Frankel				A, B, C, D	A, B, C, D, E	

LOS Acute						17.09
Mean		13.2	21.23[k], 19.77[l]			
±SD		±16.92	±21.9[k], ±18.73[l]			
Median						
Range	18.11-21.61					
LOS Rehabilitation						
Mean	42.89[h], 62.53[i], 57.98[j]	56.76	72.16[k], 70.76[l]	239	198[m], 222[n]	41.49
±SD		±34.28		±168	±10, ±9	
Median						
Range						

[h]Age 18-39, [i]Age 40-59, [j]Age 60+, [k]Men, [l]Women, [m]Treated conservatively, [n]Treated surgically

Author / **Variables Investigated**	**Cifu et al. [39]**	**Dryden et al. [23]**	**Putzke et al. [24]**	**Biering-Sørensen et al. [40]**
Year of investigation	1988-1996	1992-1994	1988-1999	1975-1984
Number of patients	2099	233	212 pairs of cases	267
Injury level	C1-C8	Cervical, Thoracic, Lumbar/Sacral/Cauda Equina		Cervical, Thoracic, Lumbar, Sacral
Injury extent ASIA Frankel	A, B, C, D			

LOS Acute				
Mean	16.3		22.1[p], 21.4[q]	
±SD	±21.4		±22.2 [p], ±19.9[q]	
Median	10.0			
Range	?-159			
LOS Rehabilitation				
Mean	86.0	26.0[o]	60.0[p], 57.8[q]	351[o,r], 261[o,s], 294[o,t], 217[o,u]
±SD	±52.6		±38.7[p], ±44.9[q]	
Median	84			329[o,r],230[o,s], 287[o,t], 196[o,u]
Range	?-499	1-450[o]		117-533[o,r], 68-627[o,s], 113-484[o,t], 56-487[o,u]

[o]Includes both acute care and inpatient rehabilitation, [p]Nongunshot, [q]Gunshot, [r]Tetraplegia Motor complete, [s]Tetraplegia Motor incomplete, [t]Paraplegia Motor complete, [u]Paraplegia Motor incomplete

Licentiatuppsatsen baserar sig på tre artiklar. Arbetet syftar till att synliggöra och analysera hur samhällsresurser i praktiken görs tillgängliga (eller inte tillgängliga) och används (eller inte används) av en grupp traumatiskt ryggmärgsskadade individer.

Den första artikeln inventerar samhälleligt stöd och service som är möjligt att söka efter en traumatisk ryggmärgsskada. Ett 25-tal stöd identifierades vilka hanteras av i huvudsak 2 olika huvudmän/aktörer. Frustration uttrycks bland brukare över denna organisation samt att känna sig kontrollerad och ifrågasatt.

Den andra artikeln analyserar hur generella etiska riktlinjer utmanas av situerad etik i designsammanhang. Motsvarigheten här är hur intentioner bakom samhällsresursers tillhandahållande utmanas av upplevelser hos den berörda vad gäller bemötande, grad av komplexitet och möjligheten att genomskåda systemen och förutse deras effekter.

Den tredje artikeln behandlar slutenvårdsanvändning för den berörda gruppen och användbarheten av dessa data för att kartlägga gruppens totala användning. Vid en validering av detta register framkom att gruppens totala slutenvårdsanvändning ej gick att fastslå.

Artiklarna diskuterar även metodologiska aspekter på kartläggningen och dokumentation av samhällsresurserna.

Den här uppsatsen hittar du också på internet:
www.certec.lth.se/dok/komplexettraumatisk

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