Communication about eating difficulties after stroke
Till Klara, Emmy och Birgit
Communication about eating difficulties after stroke
– from the perspectives of patients and professionals in health care
Stroke is one of the major causes of eating difficulties (EDs). It is one of the leading causes of death and disability and one of the most important factors contributing to health-care costs. There is a clear association between EDs after stroke and undernutrition, where studies have shown that structured screening of eating function among stroke patients can predict nutritional problems as well as need for subsequent institutional care. Reliable and valid instruments that can identify EDs exist, but there is lack of knowledge on how persons experience living with EDs after stroke. Stroke unit care is evidence-based and grounded in multidisciplinary collaboration and continuity of care. The overall aim of this thesis is to explore and describe EDs after stroke as represented by health care professionals in patient records (PRs) and transferred information, and as described by persons living with EDs after stroke. An additional aim is to explore methodological aspects related to the inclusion of persons with EDs and communication impairment in research studies.

Both quantitative and qualitative methods were used. Two studies used descriptive designs (I, II), one an explorative design (III) and one applied a methodological discussion (IV). In one of the studies PR data were used (I), in another study data were derived from three sources: PRs, screening of patients and interviews with nurses (II). Persons with EDs after stroke participated in Study III while literature, empirical data and researchers' experiences served as the data in study IV. Data were analysed by categorisation of phrases (I), content analysis (II) and descriptive statistics (I, II), by qualitative analysis (III) and by processing of literature and empirical findings in two research groups (IV).

The main findings from the studies on representation of stroke care in PRs (I, II) showed that, despite that >50% of patients in Study I and all patients in Study II had EDs, there were few signs of multidisciplinary collaboration dealing with this problem. Unsystematic screening for swallowing difficulties was routine, whereas screening for nutritional risk and EDs was lacking (I, II). Multidisciplinary discharge summaries proved to have low quality and entailed little information on patients' eating ability (I). The two EDs most frequently documented were swallowing and lack of energy to complete a meal (I,II). EDs were described in vague terms (I, II). In Study II, all patients had swallowing difficulties and most patients had lack of energy to complete a meal. The electronic information transfer tool held information on eating ability for most patients (II), but the nursing staff in residential home care perceived deficiencies in that information, even identifying several EDs not reported at discharge (II).

Experiences from persons living with EDs after stroke were presented in one main theme: Striving to live a normal life, including three sub-themes: Abandoned to learn on one's own (little support from health care professionals to learn to handle eating), Experiencing losses (loss of eating functions and loss of valued activities) and Feeling dependent in mealtime situations (III). One major finding from the methodological exploration (IV) is that creative approaches and suitable methods for inclusion of participants with EDs and communication impairment into qualitative studies can be found in the fields of aphasiology and learning disabilities. Another major finding from Study IV is that researchers need good communication skills as well as knowledge in neuropsychology.

A general conclusion is that screening for EDs should be routine in stroke care and that a multidisciplinary terminology to express EDs must be developed to provide accurate information transfer. Health care professionals need to enhance their knowledge in nutrition and provide support to stroke patients with EDs with the goal that they can eat and perform meal-related activities in accordance with their habits before the stroke. To gain access to the experiences of persons with EDs and communication impairment researchers need to test participatory approaches when planning for inclusion of those persons.

Keywords: Continuity of care, documentation, eating difficulties, nursing, qualitative interview, record audit, stroke.
Original publications

The thesis is based on the following four studies, which will be referred to in the text by their Roman numerals:


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<tr>
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<td>AKK</td>
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## SVENSK SAMMANFATTNING (SUMMARY IN SWEDISH)

Kommunikation om svårigheter att äta efter stroke – ur patienters och vårdpersonalens perspektiv

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PREFACE

As a young nurse in a geriatric ward I happened to find a well-thumbed booklet, Paralysis (in Swedish: Förlamningen) (Ågren, 1986). This little book, a 60-page autobiography by a man who had survived a stroke with severe impairments describing, among other things, his struggle with speech and swallowing problems, became the foundation for my research interest in the phenomenon of eating difficulties after stroke. Before becoming a doctoral student, I worked for several years as a nurse in stroke rehabilitation and gained experience of the multidisciplinary teamwork with patients who could neither eat nor speak in the same way as most of us can. The years have passed, stroke care has developed in many ways, both incidence and mortality have decreased significantly, and nurse specialists are working together with physicians, occupational therapists, physiotherapists, dieticians and speech-language therapists to provide evidence based and safe stroke care. Despite this progress, a large proportion of stroke survivors are unable to experience the pleasures and joys of meals and their nutritional and meal-related needs are often primarily treated as a matter of nutrition, leaving the other aspects of eating unrecognized.
SVENSK SAMMANFATTNING (SUMMARY IN SWEDISH)

Kommunikation om svårigheter att äta efter stroke
– ur patienters och vårdpersonals perspektiv

Bakgrund


Förmågorna att äta och att kommunicera är grundläggande för människlig överlevnad, för fysiologisk och mental utveckling, men också för individens identitet och upplevelse av att vara en människa i ett socialt sammanhang (Lupton, 1996). Vid förvärvade hjärnskador som stroke påverkas ofta både förmågan att kommunicera och förmågan att äta på samma självklara sätt som före insjuknandet.

Den här avhandlingen handlar om personer som har fått svårt att äta efter stroke. Den handlar också om kommunikation – kommunication med personer som har svårt att äta efter stroke, och kommunication via patientjournalen och den skriftliga informationsöverföringen vid utskrivning.
Stroke, ätande och kommunikationssvårigheter

I Sverige insjuknar årligen mellan 25 000 och 30 000 personer i stroke. Antalet personer som lever med kvarstående besvär efter en stroke beräknas till ca 100 000, varav minst 20 000 är i behov av dygnetruntvård (Socialstyrelsen, 2005). Beroende på var i hjärnan skadan finns och på skadans storlek, kan symtomen och konsekvenserna för individen spänna över ett brett spektrum. Många som får stroke får också under kortare eller längre tid flera olika typer av åtsvårigheter, ofta i kombination med till exempel halvsidesförlamning, svårigheter att kommunicera och uttalad trötthet. I en enkätuppföljning som Socialstyrelsen redovisade 2004 uppgav 7 % av de 4 700 svarande att de behövde hjälp med att äta och dricka. Mellan 40 och 80 % av patienter med stroke har någon form av åtsvårigheter, varav sväljningssvårigheter (dysfagi) är den mest utforskade. Åtsvårigheter efter stroke är ett allvarligt problem som kan leda till intorkning, undernäring, inandning av föda ner i luftvägarna, men också till känslor av skam, förnedring och beroende. Svenska omvårdnadsforskare (Axelsson, 1989; Jacobsson, 2000; Westergren, 2001) har bidragit till att bygga upp ny kunskap om hur åtsvårigheter kan identifieras och behandlas av vårdpersonal. Däremot finns få forskare som har studerat upplevelser av att leva med åtsvårigheter efter stroke. En bidragande orsak till detta kan vara det faktum att så många personer som har sådana besvär också har kommunikationssvårigheter.

Svårigheter att kommunicera efter stroke kan visa sig på många olika sätt beroende på hjärnskadans läge och utbredning. Svårigheterna kan bland annat yttra sig i form av talsvårigheter och andra språksvårigheter. I den svenska uppföljning som nämndes ovan svarade 25 % att de hade sådana svårigheter.

Att bedöma svårigheter att äta efter stroke

I den här avhandlingen har Westergrens definition av begreppet åtsvårigheter använts: ”Svårigheter som enskilt eller i kombination har en negativ påverkan på hantering och intag av mat och dryck” (Westergren et al., 2001, s. 150).

Två instrument för att bedöma förekomsten av åtsvårigheter har konstruerats och testats av omvårdnadsforskare. Det ena, Minimal Eating Observational Form (MEOF-I), består av elva bedömningskategorier ordnade inom fyra övergripande kategorier: intag av föda (sittställning, att hantera mat på tallriken, att transportera maten till munnen), sväljning (att kunna öppna och stänga munnen, att kunna hantera tuggan i munnen, att svälja), ork (att äta mer än ¼ av en normal portion, att orka genomföra en måltid, att kunna äta en måltid i normal takt) samt övriga åtsvårigheter (problem från mun och tänder,
Vård av patienter med svårigheter att äta efter stroke


Kommunikation om patienters behov i en sammanhållen vårdkedja

De nationella riktlinjerna för strokevård lyfter fram vikten av en sammanhållen vårdkedja för patienter som drabbats av stroke. I Sverige finns ett lagstiftat krav på samordnad vårdplanering då en person som kommer att behöva insatser från den kommunala vården skrivs ut från sjukhus. För personer som fått stroke och som har bestående funktionsnedsättningar är sådan vårdplanering av största vikt. I samband med utskrivning från sjukhus till kommunal vård sker även skriftlig informationsöverföring, ofta på elektronisk väg. Den information som överförs mellan vårdgivarna ska innehålla relevant information om tidigare vård, om aktuellt status och om planerade fortsatta åtgärder. På liknande sätt ställs stora krav på att patientjournalen innehåller all relevant information som kan behövas för att patienten ska få en god och säker vård.

Syfte

Avhandlingens övergripande syfte är att utforska och beskriva svårigheter att äta efter stroke ur två perspektiv: individens perspektiv och vårdpersonalens, så som det kommer till uttryck i patientjournalen och i informationsöverföringen från sjukhuset till den kommunala äldrevården. Ett ytterligare syfte är att utforska och diskutera metodologiska aspekter av planering och genomförande av kvalitativa studier som kan inkludera personer med svårigheter att äta efter stroke.
De specifika syftena är att

- beskriva multidisciplinär strokevård för patienter med åtsvårigheter så som den uttrycktes i patientjournalen och i utskrivningsmeddelanden (I)
- beskriva överensstämmelsen mellan dokumentationen om patienters svårigheter att äta i patientjournalen, jämfört med de åtsvårigheter som identifierades med hjälp av systematisk bedömning (II)
- beskriva hur sjuksköterskor och undersköterskor på kommunala äldreboenden uppfattade den information rörande åtsvårigheter som överfördes från sjukhuset (II)
- utforska och beskriva hur personer med kvarstående svårigheter att äta ca 1½ år efter stroke upplevde att leva med sådana svårigheter (III) samt
- utforska och diskutera metodologiska aspekter av urval, informerat samtycke och trötthet hos den intervjuade vid kvalitativa studier av personer som har en förvärvad hjärnskada och kommunikationssvårigheter (IV).

**Material och metod**

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Sammanfattning av resultaten

Multidisciplinär vård av patienter med stroke och ätsvårigheter (I)

Majoriteten av journalanteckningarna som rörde ätande och nutrition (78 %) var gjorda av sjuksköterskor. De typer av ätsvårigheter som förekom oftast var sväljningssvårigheter och brist på ork att genomföra en hel måltid. Även om flera patienter hade ett antal olika typer av ätsvårigheter innehöll patientjournalen oftast enbart en anteckning om patientens aktuella problem, utan professionell beskrivning av problemet med mål beskrivna, och med få tecken på att vården hade planerats och utvärderats. Multidisciplinära vårdplaner fanns för de flesta patienterna, men utan information om planering av vård relaterad till ätsvårigheter.

De flesta patientjournalerna (80 %) innehöll utskrivningsmeddelanden med någon form av vårdplan, och 77 % av dem hade information om patientens förmåga att klara ätandet. Sammanfattningsvis fanns få tecken i patientjournalen på att en multidisciplinär vård hade bedrivits med avseende på patienternas ätande.

Överensstämmelse mellan dokumentation av ätsvårigheter i patientjournalen och patientens status (II)

Två instrument användes i studien för att bedöma patienternas ätsvårigheter (Mini Nutritional Assessment-Short Form, MEOF-I) och risk för undernäring (MNA-SF). I patientjournalerna fanns inga tecken på att sådana systematiska bedömningar hade gjorts, och överensstämmelsen mellan patienternas status och informationen i patientjournalen var låg. På liknande sätt uppfattades också överensstämmelsen mellan patienternas faktiska tillstånd två veckor efter utskrivningen från sjukhuset till kommunal äldrevård och den information som överförts, som mindre bra. Dessutom hade ett antal problem med betydelse för ätandet identifierats inom äldrevården, som inte beskrevs i informationsöverföringen.

Erfarenheter av att leva med ätsvårigheter (III)

De tre personerna som intervjuades visade sig utöver stora ätsvårigheter även ha uttalade talsvårigheter, vilket kom att leda till att studie IV genomfördes. Under analysen av deras berättelser framträdde ett huvudtema, ”Kämpar för att leva ett normalt liv”. Detta huvudtema skapades av tre undertecken: ”Övergiven till att lära sig själv” (upplevelser av att inte få stöd från vårdpersonalen i att hantera
sina ätsvårigheter, en ensam kamp för att lära sig äta igen), ”Beroende av andra för att äta” (att inte kunna äta som förut, att inte kunna laga mat på grund av bristande anpassning av köket, samt, känslor av frustration och sårbarhet) och ”Förluster i ätande-sammanhang” (förlusten av det självständiga, naturliga ätandet, och av uppskattade aktiviteter som matlagning). Under intervjuerna uttrycktes dessutom att den svåraste förlusten var förlusten av det naturliga och självklara talet.

Metodologiska aspekter av urval, informerat samtycke och trötthet hos deltagare med kommunikationssvårigheter i forskningsstudier (IV)

Viss erfarenhet och kunskap om hur personer med kommunikationssvårigheter kan inkluderas i forskningsstudier finns inom andra områden än omvårdnadsforskning. Exempelvis bedrivs forskning rörande livssituationen för personer som fått afasi med kreativa metoder, där individer som själva har de aktuella problemen och personer som har stor erfarenhet av kontakter med dessa, deltar i planering och genomförande av studierna. Även Alternativ och Kompletterande Kommunikation (AKK), som används i vardagen av många personer med kommunikationssvårigheter, kan användas för att få del av individers uppfattningar i forskningsstudier. Sammanfattningsvis visade studien att metoder finns för att inkludera personer med förvärvade hjärnskador och ätsvårigheter i kvalitativa studier, att speciella färdigheter antagligen krävs av intervjuaren och att dessa personers röster är viktiga för att bygga kunskap inom området.

Begränsningar

Studie I och II har framför allt använt journaldata, varför tolkningen av resultaten måste göras med kunskap om att en stor del av informationsöverföringen mellan sjukhus och äldrevård sker muntligt via telefonrapporter och vid vårdplaneringskonferenser. Trots detta är journalen det bestående beviset på den vård som givits och planerats och ett viktigt redskap för att åstadkomma en säker vård för patienten i hela vårdkedjan.
**Slutsatser**

- Metoder finns för att identifiera ätsvårigheter hos personer som har stroke; dessutom finns tydliga såväl svenska som europeiska riktlinjer för hur nutrition ska prioriteras och hanteras inom hälso- och sjukvården. Trots detta förekom sällan bedömning av ätsvårigheter och risk för undernäring.
- Den skriftliga informationsöverföringen rörande ätsvårigheter var bristfällig, och personal i den kommunala vården uppfattade brister i informationen.
- Även om patientjournalerna innehöll många uttryck för multidisciplinärt samarbete och gemensam vårdplanering, fanns få tecken på sådant samarbete inom området ätande.
- Personer med ätsvårigheter efter stroke beskrev brist på stöd från vårdpersonal i kampen för att lära sig hantera sina ätsvårigheter.
- Strategier och metoder finns som borde provas för att inkludera personer med ät- och kommunikationssvårigheter i kvalitativa studier. Sådana studier är av stor vikt då dessa personers röster annars riskerar att inte bli hörda.
INTRODUCTION

"In the last eight months I have swallowed nothing save a few drops of lemon-flavoured water and a half teaspoon of yoghurt, which gurgled noisily down my windpipe. The feeding test - as they grandly called this banquet - was not a success. But no call for alarm: I haven’t starved. By means of a tube threaded into my stomach, two or three bags of a brownish fluid provide my daily caloric needs. For pleasure, I have to turn to the vivid memory of tastes and smells, an inexhaustible reservoir of sensations. Once, I was a master at recycling leftovers. Now I cultivate the art of simmering memories" (Bauby, 1997, p. 35).

This vivid and emotional picture of problems, memories and senses related to eating is one of the few descriptions of living with eating difficulties after stroke that could be found in the popular literature. In his diary from the rehabilitation hospital the former editor-in-chief of the French Elle Magazine, Jean-Dominique Bauby, gives us short, lyrical glimpses from his life as a person suffering from the “locked-in syndrome” after a cerebro-vascular accident in the brainstem. Despite his helpless state, he was able to describe to us his desire to communicate and his reflections, memories and feelings related to food and eating.

The ability to eat is fundamental not only to survival and to maintaining a sufficient nutritional state for growth and physiological and mental development, but also for our sense of self and of being in the world. Food, eating and mealtime activities can be everyday, taken-for-granted phenomena which we do not give conscious attention. It can be joyful celebrations and sensual pleasures but also occasions characterised by feelings of disclosure, embarrassment, fear and disgust (Lupton, 1996). Biasin described the human mouth as, “the ambiguous locus of two oralities: one articulates the voice, language; the other satisfies a need, the ingestion of food for survival first of all, but also for a pleasure that becomes juxtaposed with the value of nourishment" (Biasin, 1993, p.3).

For human beings and for all forms of social life, the want and desire to communicate is fundamental. It is so fundamental that Bauby developed a system for communication via blinking with his right eye, the only part of his body that he could control. It is also so fundamental that the United Nations stated in the Universal Declaration of Human Rights (article 19) that everyone has the right to freedom of opinion and expression (United Nations, 1948). Striving to communicate has been documented in rock paintings 40.000 years ago and in pre-writing symbols from 10.000 BC. Aristotle (384-322 BC) claimed that the written language symbolised speech, whereas the spoken language was a symbol
for thoughts reflecting the surrounding world (Allwood, 1983). For many thousands of persons impaired by stroke, however, the ability to communicate via written or spoken language will be temporarily or permanently impaired, as will their ability to eat in a socio-cultural normal manner.

This thesis is about individuals who have experienced a stroke. Stroke care is based on multidisciplinary collaboration: the perspective of this thesis is also multidisciplinary, and not exclusively a nursing perspective. However, multidisciplinary collaboration *per se* is not the main focus of this thesis. Depending on circumstances and context individuals with eating difficulties after stroke are referred to as patients, residents (in residential home care), persons or individuals. Similarly, persons caring for individuals with stroke are named according to their profession, or when referring to a multi-professional group, as health care professionals in hospital context and as nursing staff in the residential home care context. Care for older persons in the municipality is denoted as residential home care.
Eating after stroke

Stroke is one of the major illnesses that can cause eating difficulties. It is the third cause of death and the most common cause of disability in Western countries (Wolf & Ågostino, 1998; Stegmayr & Asplund, 2003; Carandang et al., 2006; Tobias et al., 2007; Jungehulsing et al., 2008). In Sweden, 25–30,000 individuals suffer from stroke each year. Of these, 20% are below retirement age (65 years). After hospital care, 85% of individuals with first-ever stroke are able to return to their homes, with or without support from municipal home care or family carers. The number of persons surviving a stroke has increased considerably during the past decades and Swedish persons who have experienced a stroke constitute a growing, older population of more than 100,000. This is a large group in need of medical follow-up, rehabilitation. In addition, at least 20% of them need comprehensive nursing care (Avendano et al., 2005; Socialstyrelsen, 2005; Norrving, 2007; Riks-Stroke, 2007).

Eating, food and mealtime activities are studied within several scientific traditions, showing conceptual differences in describing and understanding these phenomena. In this thesis the insider perspective (i.e. the perspective of the individual who experiences eating difficulties after stroke) and the perspective of health care professionals as represented in documentation and information transfer in multidisciplinary care for stroke patients is investigated. Until the 1980s, eating difficulties after stroke were scarcely recognised as research issues for nursing science. However, in 1988 and 1989 two pioneer dissertations were presented: Carr in United Kingdom (Carr, 1988) and Axelsson in Sweden (Axelsson, 1989). Those nurse researchers and their co-workers started to explore and describe the multi-faceted phenomenon of eating (Axelsson et al., 1984; Carr & Hawthorn, 1988a, b; Axelsson et al., 1989). Several nurse researchers have continued that work but there is still no commonly acknowledged definition of eating difficulties after stroke. In this thesis the following definition by Westergren and colleagues is used:

Difficulties that, alone or in combination, negatively interfere with the preparation and intake of served food and/or beverages.

(Westergren et al., 2001, p. 150).
The aetiology of eating difficulties after stroke is multi-faceted and complex with many difficulties that are caused by brain damage and its manifestations, and depending on the severity, location and spreading of the brain damage. Stroke manifestations causing eating difficulties range from inability to maintain upright posture, vertigo, loss of upper limb motor control and sensation to facial paresis, oral sensory and motor disturbances, swallowing problems (dysphagia) and communication, visual deficits and attention deficits (Axelsson et al., 1989; Jacobsson et al., 2000a; McLaren & Dickerson, 2000; Westergren et al., 2001). For example, damage in the MCA (media cerebellar artery) territory will probably cause contra-lateral hemiparesis and central facial paresis, whereas damage in the brainstem may cause vertigo, nausea and dysphagia, or even a “locked-in syndrome” where alertness and sensibility are preserved but motor function is limited to eye movements and breathing (E-medicine, 2008) such as in the case of J-D Bauby (1997). In a person with stroke eating difficulties also may be caused by, for example, various oral and dental problems, fatigue, crisis reaction to the stroke accident, depression and other medical circumstances.

**Aspects of eating difficulties after stroke**

The main body of knowledge on the various aspects of eating difficulties after stroke is in the area of dysphagia, in which studies have been published since the 1960s, resulting in the development of methods for diagnostics, treatment and education (see, for example, Veis & Logemann, 1985; Logemann, 1994; Westergren et al., 1999; Ramritu et al., 2000; Bath et al., 2002; Hägg, 2007; Martino et al., 2008). Although dysphagia occurs in 20–50% of patients in the acute phase of stroke, it has been found to resolve in many cases within 2–3 weeks (Barer, 1989; Westergren et al., 1999). Dysphagia may cause life-threatening airway obstruction, aspiration pneumonia, undernutrition and ultimately death (Barer, 1989; Dàvalos et al., 1996; Leder & Espinosa, 2002). Studies have shown that the presence of dysphagia at the time of admission to hospital is independently associated with poor outcome, including poor functional ability, institutionalisation and increased mortality. An association between dysphagia on admission and poor outcome persists for 6 months after stroke. It may even be the strongest predictor of outcome and it is probably independent of any aspiration that may occur (Smithard et al., 1996; 2007). Studies have also shown that, in comparison with objective measures, persons with dysphagia underestimate the severity of swallowing problems (Elmståhl et al., 1999), and those persons with good awareness of their dysphagia have safer
intake of food and swallowing than those with poor awareness (Parker et al., 2004).

In hospitalised persons with stroke various eating difficulties appear in 40–80% of the population, with 16%–50% requiring assisted eating (Westergren et al., 2001; Westergren et al., 2002a; Poels et al., 2006). In a Swedish national survey 7% of persons who had experienced a stroke reported a need for assisted eating two years after discharge from hospital (Socialstyrelsen, 2004). Eating-related factors have been identified as important aspects of quality of life after stroke (Perry & McLaren, 2004), and depressed mood and poor nutritional status may create a vicious circle of deterioration (Paradiso et al., 1997). A theory of the willingness to eat has been proposed, describing internal and external factors affecting older persons’ appetite. Such factors can be mood and individual values as well as food, eating milieu and mealtime fellowship (Wikby & Fägerskiöld, 2004).

Obviously, there is a close and important relationship between eating difficulties and undernutrition. Although the focus in this thesis is not on the nutritional aspects of eating difficulties, nutritional effects of an individual’s eating difficulties are important challenges for nurses and other health care professionals. Therefore, a short summary of relevant nutrition research is presented, as well as a summary of guidelines governing nutritional care in hospitals.

Multiple studies have been performed during the past 20 years on nutritional status among hospitalised patients in general and on patients affected by stroke in particular (Kondrup et al., 2002; Westergren et al., 2002a; Furman, 2006; Jönsson et al., 2008). Prevalence of undernutrition in hospitalised patients ranges from 20% to 50% depending on the criteria used to determine undernutrition and on individual characteristics (Westergren et al., 2001; FOOD Trial Collaboration, 2003; Norman et al., 2008). Serious consequences of undernutrition, such as increased incidence of infections (Chandra, 2004), slow recovery and poorer functioning in activities of daily living (Bischoff et al., 2006) and significantly longer hospital stay (Kondrup et al., 2002) have been established. Increased risk for undernutrition has been found among persons with stroke in need of assisted eating (Saletti et al., 2000; Westergren et al., 2001; Westergren et al., 2002a). The relationship between oral health and eating function is self-evident, but nevertheless oral health is often compromised in older hospitalised patients and given low priority by nursing staff (Paulsson, et al., 2007). A relationship between poor oral health status and undernutrition in older patients has been demonstrated (Andersson, et al., 2002) and systematic
assessment of oral health in hospitalised patients has been suggested (Paulsson, et al., 2007). However, thus far evidence-based oral care interventions for stroke patients are lacking (Brady et al., 2006).

To conclude, there is a close relationship between eating difficulties after stroke and undernutrition. Several studies have shown that structured screening of eating function among stroke patients can predict nutritional problems as well as the need for subsequent institutional care. To date, focus has mainly been on dysphagia but recent studies have highlighted the impact of other eating difficulties on long-term outcomes.

**Identifying eating difficulties**

Based on the work of Axelsson, Westergren and colleagues have identified four main categories of eating difficulties: ingestion, deglutition, energy and other difficulties. Ingestion refers to sitting position, handling food on the plate and transporting it to the mouth. Deglutition concerns ability to open and close lips, handling of food in the mouth and swallowing. Lack of energy includes alertness, eating speed and quantity of consumed food (Westergren et al., 2002a; 2002b). Other eating difficulties concern appetite and chewing problems or other oral problems. Similar components of the eating process have been established by Jacobsson and colleagues (1996), McLaren and Dickerson (2000), Perry and McLaren (2001) and Poels and colleagues (2006). The components of the eating process have been operationalised in the form of two instruments for observation of eating (McLaren & Dickerson, 2000; Westergren, 2006). Recently, the Minimal Eating Observational Form (MEOF-I) was tested for reliability and validity in a Swedish context with older patients in hospital and residential home care. The instrument showed good reliability and validity. After factor analysis, it was further developed into three categories (ingestion, deglutition and energy/appetite) (MEOF-II, Westergren et al., in press). The instrument has been shown to predict undernutrition, need for assisted eating, length of stay in hospital and level of care after hospital discharge (Westergren et al., 2002b; in press). Systematic screening for dysphagia has been highlighted as an important intervention for early identification of swallowing difficulties. Invasive and non-invasive methods for such identification exist.

A structured eating training programme after stroke has been tested to a limited extent, including assessment of the components in the eating process, individual planning of interventions in the mealtime situation and the individual’s experiences of eating (Axelsson et al., 1986; 1988; Jacobsson et al., 1997; 2000b).

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Institutional eating for older patients

From a broader, socio-cultural perspective, eating difficulties after stroke and difficulties that are caused by other medical conditions among older persons may comprise problems with meal-related activities such as cooking, food shopping and social interaction at mealtime. In a home milieu the meal is something personal, private and intimate based on family habits and local culture. In contrast, in institutions (for example, hospitals and residential homes) the occasion for eating food has been described as an activity to satisfy nutritional needs with consideration taken to economy (Mattsson-Sydner, 2003). As for eating difficulties after stroke, Swedish nurse researchers have made an important contribution to the knowledge base on eating in care institutions where older persons with stroke constitute a large percentage of the patients. Sidenvall and co-workers, who studied meals in geriatric care, described the meeting of two conflicting cultures: older patients admitted for care, with their individual meal habits and incorporated understanding of desirable patient behaviour, and health care professionals who shared an institutionalised culture. In that institutional culture meals were ritualised and organised in the same way as meals in society; that is, both older patients and nursing staff strove towards civilised manners, purity and order. One of the norms among health care professionals guiding meal procedures was to provide a home-like situation for training purposes. For example, patients were seated together at meals, which made serving easier and good supervision for patients with swallowing or other eating difficulties could be achieved. The older patients, on the other hand, experienced reduced well-being at mealtimes because of the cultural conflict between their personal norms and those of the institution (Sidenvall, et al., 1994; 1996; 1999). Another study performed in residential home care was based on the hypothesis that residents would appreciate a more home-like milieu, small groups dining together and actively participating in meal preparation and food choices (Kofod & Birkemose, 2004). The relationship between milieu and organisation and residents’ perceptions, however, was not clear and thus the hypothesis was falsified. The mealtime situation was not perceived as home-like by the residents; they were confronted with new roles for collective eating; they had to eat together with persons they were not acquainted with; and they had to manage different eating difficulties in that situation. The researchers concluded that residents and nursing staff had different perceptions of the meal situation, and that the nursing staff need to acquire competence to handle the social aspect of meals (Kofod & Birkemose, 2004). A recent study performed in two Internal Medicine hospital wards reported low priority on meals and nutrition in older patients that did not
receive enough assistance at mealtimes, with little attention to amount of food eaten by patients and to the social interaction during meals (Xia & McCutcheon, 2006).

To conclude, institutional eating in a care context has been studied to some extent, with results suggesting the need for the priority of meals and food matters in care institutions, including changes in institutional culture related to meals and nutrition.

**Eating after stroke from the insider perspective**

The effects of a stroke may be profound, affecting visible features as well as the sense of self and of being in the world. However, knowledge about individual experiences of living with eating difficulties after stroke is poor, with only a small number of qualitative studies published (Jacobsson *et al.*, 2000a; Perry & McLaren, 2003b; Jordan *et al.*, 2006). In the prose literature there are multiple narratives of life after stroke, but with few references to eating and mealtime experiences (Åhgren, 1986; Bauby, 1997; Thoresen, 1997). Living with such difficulties has been demonstrated to cause suffering, including fear of choking, shame about one’s appearance, humiliating dependency in eating situations (Carr, 1988; Rosenbek, 1995; Jacobsson *et al.*, 2000a), practical difficulties at mealtime and “a burden of treatment” for persons fed by percutaneous endoscopic gastrostomy (PEG) (Rickman, 1998; Jordan *et al.*, 2006). More positive experiences have also been described, such as avoiding receiving help and striving for independence and a normal life (Perry & McLaren, 2003a, 2003b; Gustafsson & Andersson, 2004). To our knowledge, no study has been published on experiences of assisted feeding. However, one study (Martinsen, *et al.*, 2008) reported on such experiences from persons with spinal cord injury. Assisted feeding was described to be a multi-faceted construct of the paralysis as a condition of life, a necessity to face the altered meal, need for sensitive cooperation with the carer, realisation of own values around meals, balanced use of meal-related devices and negotiating a relationship with the carer. The findings stressed the importance of adjustment of feeding to the individual, including personal preferences as to the use of assistive devices, of acknowledging personal and social norms at mealtime and of giving high priority to the continuity of those involved in feeding (Martinsen, *et al.*, 2008).

To summarise, reliable and valid instruments to identify eating difficulties exist, but there is little knowledge on how living with eating difficulties after stroke is experienced by individuals, both in different phases of the illness trajectory and under different conditions (for example, eating via PEG or being dependent on assisted feeding).
Care for persons with eating difficulties after stroke

Nutritional care

The Council of Europe Committee of Ministers published a resolution for nutritional care in European hospitals in 2003 (Council of Europe, 2003). The recommendations in that resolution are detailed and put high demands on care providers to organise and educate staff for high quality and multidisciplinary nutritional care. Among other recommendations, screening for nutritional risk, identifying causes for undernutrition and providing nutritional support are emphasised. In Swedish hospitals, however, that resolution has not been implemented to the degree necessary to provide effective nutritional care (Johansson et al., 2006). In addition, the European Society for Clinical Nutrition and Metabolism (ESPEN) (Kondrup et al., 2003) published guidelines for nutritional screening applicable to different care settings. The purpose of the guidelines was to propose methods for nutritional screening as a common basis for further nutritional care (Kondrup et al., 2002). In a Scandinavian survey, however, registered nurses and physicians working in various specialities where nutritional problems were common reported insufficient knowledge in nutritional care (Mowe et al., 2008). Moreover, in a study on residential home care it was found that managers, kitchen personnel and nursing staff were not educated in nutritional care (Mattsson-Sydner & Fjällström, 2005). In another study in residential home care registered nurses were reported to lack specific knowledge on how to plan for residents with eating difficulties after stroke (Kumlrien, 2005).

Guidelines for stroke care

Ample scientific evidence supporting treatment in stroke units is available (Stroke Unit Trialists’ Collaboration, 2007) and European stroke experts have agreed on which quality indicators should be used and a common European stroke strategy has been developed for such care (Kjellström et al., 2006). In Sweden, all hospitals caring for stroke patients are engaged in a unique, national quality register to evaluate the quality of stroke management (Asplund et al., 2003). The stroke unit strategy is based on the multidisciplinary team (usually a physician, registered nurse, assistant nurse, physiotherapist, occupational therapist, speech-language therapist and social worker), coordinated multidisciplinary teamwork, regular programmes for education and training of staff and with an emphasis on continuity of care. In the recent National Swedish guidelines for stroke care (Socialstyrelsen, 2005), advice on relevant nursing interventions related to eating difficulties was presented. Those recommendations, however, are based on
clinical praxis and expert consensus, since evidence based nursing interventions are lacking (Socialstyrelsen, 2005, p. 117).

**Table I.** Nursing interventions among patients with eating difficulties after stroke according to the Swedish National guidelines for stroke care (Socialstyrelsen, 2005).

<table>
<thead>
<tr>
<th>The eating process</th>
<th>Specific interventions</th>
<th>General interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Food intake:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sitting comfortably during the meal</td>
<td>Adaptation of cutlery, glass, mug Consultation of expert staff</td>
<td>Assisted eating Feeding Eating training Enteral/parenteral nutrition Adjustment of mealtime environment</td>
</tr>
<tr>
<td>To cut up food on the plate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>To transport food to the mouth</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>The swallowing process:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>To open and close lips</td>
<td>Modified food consistency Mouth massage Specific techniques for swallowing and positioning of the head while swallowing Consultation of expert staff</td>
<td>Assisted eating Feeding Eating training Enteral/parenteral nutrition Adjustment of mealtime environment</td>
</tr>
<tr>
<td>To manipulate food in the mouth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>To swallow</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Energy:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>To eat a full meal</td>
<td>Nutritional supplements Energy and protein-enriched meals Plan activities so that patient has energy to eat Provide smaller but more frequent meals during a day Consultation of expert staff</td>
<td>Assisted eating Feeding Eating training Enteral/parenteral nutrition Adjustment of mealtime environment</td>
</tr>
<tr>
<td>To have energy to complete a meal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>To complete a meal in normal time</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
In Sweden, as well as in other countries, national guidelines for stroke care stress the importance of not only nutritional care but also appropriate discharge planning and information transfer to other providers in continuous stroke care. Swedish guidelines define continuity of care, or “care chain”, as “a coherent care episode, a series of coordinated interventions including patient information and education” (Socialstyrelsen, 2005, p.149, in Swedish, author’s translation). The purpose of continuity of care is to guarantee adequate and prompt investigations, diagnosis, treatment and rehabilitation, characterised by interprofessional collaboration throughout the entire care process and with care plans and rehabilitation plans as important tools.

To conclude, the stroke unit concept is evidence-based and includes interventions to guarantee continuity of care, which is an important aspect of communication in relation to patients who have survived a stroke. Additional to directives on the importance of continuity of care, European authorities, based on an extensive body of knowledge, also mandate systematically organised nutritional care. However, knowledge on nutritional care among physicians and registered nurses has been found to be insufficient.

**Communication about eating difficulties after stroke**

Communication is a core concept in this thesis. Communication is manifested in patient records, information transfer at discharge and in interviews with nurses and with persons who have experienced a stroke. The word communication, in Latin communicatio, comes from communicare, meaning, “to impart, share” and communis, meaning, “to make common” (Online Etymology Dictionary). People communicate in all phases of life, from birth to death, whether they want to or not and whether deliberately or not. Development of communicative ability and satisfaction of the desire to communicate are important aspects of the individual’s physical, social and cultural development. Language or codes for expressing information and physical media for transferring this information are basic prerequisites for communication (Ogden & Richards, 1923/1989; Thompson, 2003). Language is necessary for the exchange of complex and abstract expressions of ideas and reasoning that is desirable in all relations. The lexical content of a message, that is the words themselves, can only convey meaning if the receiver understands them, an obvious but sometimes overlooked fact in caring relations (Hemsley, *et al.*, 2001). Communication is understood and studied within several scientific traditions (for example, as a monologic process of sending messages from transmitter to receiver or as a dialogic, mutual creation of meaning involving both cognition and communication) (Mead, 1934/1972;
Linell, 1998; Thompson, 2003). There exists a formidable body of communication theory. Linell described monologic communication as “the mainstream epistemology in most contemporary approaches to language, notably in linguistics, cognitive psychology, computer sciences and largely within communication studies” (Linell, 1998, p.17). Dialogism, on the other hand, was described as a continuous, dynamic process, stressing the interactional (mutual other-oriented) and contextual aspects of human discourse (Linell, 1998).

In this thesis two aspects of communication have been studied: spoken communication and written communication. Spoken communication has an acoustic medium, implying that apprehending speech presupposes a hearing function, but also a short-term memory function and the capacity to de-code messages. An obvious prerequisite for successful spoken communication is the ability to speak and to articulate the intended message. Spoken communication not supported by a preformulated text or supporting notes demands that the speaker is able to rapidly construct the intended meaning. Problems with both prerequisites mentioned may result in faults and misconceptions, as well as in failure to get the message through to the other person. Spoken communication usually takes place in a certain context with both speaker and listener present. They can see one another and speech can be complemented with gestures and other non-verbal forms of communication. These conditions are obviously altered if the spoken communication occurs as a telephone conversation such as nursing “handover” or if the person who is listening is blind (Linell, 1978; 1998).

Written communication has an optic medium, which is constituted by signs that can be registered by vision. In addition, written communication is permanent and can convey complex structures. The purpose of written communication is often that it can be read in other contexts (for example, patient records). However, the writer cannot know at the time of writing all the occasions when the message will be read, as well as all the persons who will be reading it. Generally, writer and reader probably have few common conditions (for example, hospital nurses writing discharge summaries to nurses in residential home care) (Linell, 1978; 1998).

Non-verbal communication or “body language” refers to the bodily movements which accompany speech and which add meaning to the interaction. Non-verbal communication includes several components, such as facial expression, eye contact, posture, orientation in relation to the other, proximity to the other, fine movements (for example, a nod of the head or a wave of the hand) and gross movements (for example, walking) (Dimbleby & Burton, 1992; Thompson, 2003). Non-verbal communication is of crucial significance for persons with
communication impairment (for example, aphasia after stroke), being partly cultural and partly personal, where body language expresses something about the person’s identity or sense of self (Fiske, 1990).

**Informational continuity of care - communication about stroke patients' needs at discharge from hospital to residential home care**

Continuity of care has been reported as a key component of patient safety in all health care transitions (Hellesø et al., 2004; Bookvar & Burack, 2007). Continuity of care occurs in many different contexts – as well as inside (intra) and between (inter) organisations – showing partly different characteristics. However, there are two common distinctive features of continuity of care, namely that it is about an individual patient and about care delivered over time. Both elements must be present for continuity of care to exist (Haggerty et al., 2003). Written information (for example, the information in patient records) often deal with the patients’ medical conditions, leaving such important information on their functional abilities as eating, dressing and mobility (Jensdóttir et al., 2008), as well as preferences, values and social context undocumented. That kind of information is often only shared verbally among health care professionals who care for the patients (Haggerty et al., 2003), causing risk for gaps in information transfer and thus lack of informational continuity. Informational continuity, which is defined as “the use of information on past events and personal circumstances to make current care appropriate for each individual”, is one of the three dimensions of continuity of care proposed by Haggerty and colleagues (Haggerty et al., 2003, p. 1220). The two additional dimensions of continuity are management continuity and relational continuity. Relational continuity will not be discussed in this thesis. Hellesø and colleagues (2005) have suggested that exchange of information across organisations is both a process in itself and a precondition for nurses' ability to provide continuity of care, pointing out challenges related to information transfer such as incomplete and delayed information and lack of or inadequate information. The authors also concluded that further research is needed on what constitutes adequate organisation and content of information for continuity of nursing care and that technology, such as electronic patient records, does not solve the question about what is relevant information concerning a specific patient in a specific caring situation (Hellesø et al., 2005). Similar conclusions were drawn by Payne and co-workers (2002), who also highlighted causes for breakdown of information transfer, including time pressure, lack of role understanding, not making discharge planning a priority,
lack of co-ordination and fragmentation of information (Payne et al., 2002). One important aspect of informational continuity of care that has come in focus in recent years is the use of IT solutions (for example, electronic patient records and discharge summaries). Integration of electronic records from different care providers is suggested to achieve adequate information access and documentation at the point of care (Hägglund et al., 2007). Continuity of care has been described from the perspectives of patients and health care providers:

For patients and their families, the experience of continuity is the perception that providers know what has happened before, that different providers agree on a management plan, and that a provider who knows them will care for them in the future. For providers, the experience of continuity relates to their perception that they have sufficient knowledge and information about a patient to best apply their professional competence and the confidence that their care inputs will be recognised and pursued by other providers (Haggerty et al., 2003, p. 1221).

The patient record is a legal document providing evidence of care provided to the individual patient, an important tool for planning and evaluation of patient care and a data source for research and quality improvement. Swedish registered health professionals are obliged to document in the patient record all relevant information on the individual’s conditions, including planned and performed interventions and information provided to the patient (SFS 2008:355). A comprehensive care plan continuously updated is an important prerequisite for management continuity and thus represents continuity of care of high quality (Haggerty et al., 2003). Patient records, care plans and information transfer are increasingly being provided in electronic applications, but much developmental work is still needed to accomplish integrated systems in which information from all relevant systems is easily accessible, providing decision support at the point of care (Ehrenberg, et al., 2004).

**Gaining access to experiences from persons who have survived a stroke – the insider perspective**

Communication impairment is common among persons who have survived a stroke. Two stroke-related types of communication impairment are aphasia and dysarthria. Aphasia is a language disorder that can affect many aspects of communication including speech, writing, reading and understanding of spoken
communication (Parr et al., 1997; Yorkston et al., 2001). Speech disorders (dysarthria) involve disturbances in the muscular and respiratory control of the speech mechanism and are often related to dysphagia (Nicolosi et al., 2004). Studies have shown that 20% or more of people who have had a stroke experience language or speech impairment (Subcommittee on Brain and Behavioural Sciences, 1991; Socialstyrelsen, 2004). In the Swedish survey referred to earlier 4,700 persons reported the consequences of stroke on their daily lives two years after the stroke. Of these 4,700 respondents, 25% reported speech problems, 33% had problems with reading and almost 50% had writing problems (Socialstyrelsen, 2004).

Qualitative researchers that intend to study experiences of life after stroke have mainly relied on interview data (see, for example, Barker et al., 2004; Faircloth et al., 2005; Kvigne et al., 2003; Murray & Harrison, 2004). Because a large percentage of persons with stroke have some degree of communication impairment, qualitative interviews will be a challenge to researchers. Thus, the voices of those persons might not be heard in the literature because of the result of sampling bias in research. One phenomenon at risk for not being thoroughly investigated because of such methodological problems is eating difficulties after stroke. This is because eating difficulties and communication impairment often co-exist. Strategies for interviewing persons with communication problems after stroke have been discussed by Philpin and colleagues (2005) who also made recommendations for the interview situation. These recommendations include (a) using interviewers experienced in communicating with persons who have impaired speech, (b) listening carefully, encouraging and prompting informants during the interview, (c) writing verbatim instead of recording the informants’ speech when it is very unclear, with frequent pauses and few words, (d) offering the informants a list of the broad areas of inquiry in advance, (e) accepting written answers and (f) using circumstantial field notes (Philpin et al., 2005).

A common sampling strategy in qualitative research is to search for informants who can express their experience in a discourse or in a rich narrative. Such a strategy will exclude persons with communication impairment, however. Already in 1986, Sandelowski described the problem with ‘elite bias’, choosing the most articulate and accessible members of the group under study (Sandelowski 1986). In a meta-study of 293 qualitative studies investigating chronic illness Thorne and co-workers (2002) found that only a few studies involved participants with impaired verbal communication. The researchers concluded: “much of the diversity inherent in chronic illness experiences might have been rendered invisible within our research literature” (Thorne et al., 2002,
The commonly used procedures for sampling may thus exclude large groups of persons with special experiences of life after stroke such as those with eating difficulties. In a few studies recognising this problem researchers chose to have next of kin completing and interpreting the experiences and opinions of persons with communication impairment (for example, Mitchell & Koch, 1997; Perry & McLaren 2003b). According to Yorkston and colleagues, “People communicate in the context of their everyday life. This includes the roles they choose or are expected to play, the circumstances in which they exist, and the community culture that defines the natural environment” (Yorkston et al., 2001, p. 126). This implies that another person never can represent the individuals’ experiences.

To conclude, the two aspects of communication addressed in this thesis are written and verbal communication. Examples of written communication for stroke patients are patient records and discharge planning documents in different media. Verbal communication accompanied by “body language” – or rather difficulties with verbal communication – are frequent problems for persons who have experienced a stroke and eating difficulties, resulting in risk that those individuals will not be given the opportunity to participate in qualitative interviews.
RATIONALE FOR THE THESIS

The reviewed literature has indicated that eating difficulties after stroke may cause risk for suffering related to undernutrition, severe medical complications and social isolation. Reliable and easy-to-use instruments for early identification of nutritional risk and eating difficulties are available for nurses in hospitals and in residential home care. However, eating difficulties among stroke patients are often unrecognised by health care professionals despite that systematic observation of eating ability can predict need for assisted eating, length of stay and level of care at discharge. In addition, health care professionals have expressed lack of knowledge in nutrition. Knowledge on how living with eating difficulties after stroke is experienced by the individual is scarce because those eating difficulties are often accompanied by communication impairment, which excludes those persons from participating in qualitative studies. Another aspect of care for persons with eating difficulties after stroke showing an insufficient knowledge base is communication about the patient or documentation and information transfer to provide continuity of care. Therefore, this thesis is an attempt to increase the knowledge about eating difficulties after stroke, how those difficulties are experienced by individuals, identified and documented by nurses and other health care professionals in continuous stroke care and how persons with eating difficulties after stroke can be included in research studies.
AIMS

The overall purpose of this thesis is to explore and describe eating difficulties after stroke from two perspectives. One perspective is the perspective of health care professionals, as documented in patient records and in information transfer in multidisciplinary and continuous stroke care (that is the representation of eating difficulties in written discharge information transferred from hospital to nursing staff in residential home care) and the accuracy of that information as perceived by nursing staff. The other perspective is the insider perspective, which is the perspective of individuals who live with eating difficulties that are caused by stroke. Another purpose, related to the insider perspective, concerns examining methodological aspects related to inclusion of persons with eating difficulties after stroke in research studies.

Specific aims are

- Study I: To describe multidisciplinary stroke care for patients with eating difficulties as represented in patient records and in discharge summaries.

- Study II: To describe the accuracy in information transfer on eating difficulties in stroke patients discharged from hospital to residential home care. More specifically, to determine the accuracy in documentation of patients’ eating difficulties in relation to patient status, and how registered and assistant nurses in residential home care perceived eating-related discharge information transferred from hospital.

- Study III: To explore how persons affected by stroke experienced living with eating difficulties 1½ years after hospital discharge.

- Study IV: To explore methodological issues related to sampling, obtaining informed consent and fatigue in qualitative interviews involving participants with communication impairment after stroke and other acquired brain damages.
MATERIAL AND METHODS

This thesis consists of four studies with separate data gathering procedures. The three empirical studies were conducted from 2002 to 2008 in day care rehabilitation and stroke unit settings in a local Swedish hospital and in residential home care in three adjacent municipalities, including one home care setting. The fourth study was based on data and experiences gained from two empirical studies, one in a Swedish, and the other in a Canadian context.

Design

Because knowledge about the phenomena in focus in this thesis is limited, a descriptive and an explorative design were used in the empirical studies.
Table II: Overview of the studies included in the thesis.

<table>
<thead>
<tr>
<th>Study</th>
<th>I</th>
<th>II</th>
<th>III</th>
<th>IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Design</td>
<td>Descriptive</td>
<td>Descriptive</td>
<td>Explorative</td>
<td>Methodological exploration</td>
</tr>
<tr>
<td>Focus</td>
<td>Multi-disciplinary and continuous care for persons with stroke and eating difficulties.</td>
<td>Informational continuity for stroke patients with eating difficulties. Accuracy of discharge information as perceived by receiving nurses in municipal care.</td>
<td>Experiences of living with eating difficulties 1½ years after stroke.</td>
<td>Sampling, informed consent and fatigue in participant and researcher engaged in qualitative interviews with persons experiencing communication impairment.</td>
</tr>
<tr>
<td>Participants/Data sources</td>
<td>Consecutive sample of 59 patient records and discharge summaries.</td>
<td>Convenience sample of 15 triads consisting of one stroke patient discharged to municipal care, his patient record and two receiving nurses (one registered and one assistant nurse).</td>
<td>Purposeful sample of three persons with severe eating difficulties.</td>
<td>Literature and two research groups’ experiences as well as findings from two qualitative studies: study III and a study on six persons with traumatic brain injury.</td>
</tr>
<tr>
<td>Data collection</td>
<td>Record audit.</td>
<td>Record audit, screening for nutritional risk and eating difficulties. Structured interviews.</td>
<td>Repeated, qualitative interviews and participant observations</td>
<td>Literature review, review of textbooks and of interview transcripts.</td>
</tr>
<tr>
<td>Data analysis</td>
<td>Categorisation of phrases and descriptive statistics.</td>
<td>Content analysis and descriptive statistics.</td>
<td>Qualitative analysis.</td>
<td>Collaborative processing of literature and empirical findings, as well as experiences in the two research groups.</td>
</tr>
</tbody>
</table>
Settings

The settings in this thesis were different parts of the stroke “care chain” (one stroke unit at a local, Swedish hospital, a day-care rehabilitation unit at the same hospital, six residential home care units in three municipalities, whereof two were rehabilitation units, one home care team and one private flat located in a residential home). In accordance with Swedish law, the county council has the responsibility to provide acute hospital care while municipalities are responsible for long-term care, housing and other services for older persons needing such support. The National “aging-in-place” policy has the consequence that older persons moving to residential home care are frail, old and in need of comprehensive nursing care. Moreover, stroke patients with substantial care needs are discharged back to their homes (SFS 1990:1404; SFS 2001:453).

The hospital was a local hospital with 100 beds guided by a policy that all patients with stroke should be cared for in the stroke unit. This stroke unit organisationally belonged to the Department of Internal Medicine, had eight beds for acute stroke and eight for stroke rehabilitation and was thus a comprehensive stroke unit (Stroke Trialists’ Collaboration, 2007). During the data collection period for study II, however, the stroke unit had a temporary reorganisation resulting in a mix of internal medicine patients together with stroke patients.

The stroke unit strategy is based on the multidisciplinary team; the actual unit had a ward physician (specialised in neurology), registered nurses, assistant nurses, physiotherapists and occupational therapists. Furthermore, a speech-language therapist and a social worker participated in care conferences and conducted individual consultations. Multidisciplinary teamwork was coordinated via regular care conferences. Additional distinguishing features for the stroke unit, which was also practiced in the actual unit, were involvement of relatives in care planning and regular programmes for education and training of staff (Kjellström et al., 2007; Stroke Trialists’ Collaboration, 2007). The day-care rehabilitation unit, where participants for study III were recruited, was next door to the stroke unit. Patients with varying medical diagnoses had individual training at this day-care rehabilitation unit for predetermined periods of 1-2 months. Staff at the day-care clinic were occupational therapists, physiotherapists and assistant nurses.

The three adjacent municipalities where data collection took place were situated in a rural area. In this area a variety of residential home care units existed, including short-term care units, rehabilitation units, specialised dementia units and residential homes with different staff personnel. In one case (study II),
two nurses from a home care team in one of the municipalities also participated. During the data collection period, only one of those residential home care units was visited by the researcher for data collection (this visit took place when interviewing one of the informants in study III). In study II, staff from the six included residential homes participated via telephone.

Table III. Data collection sites in the three empirical studies.

<table>
<thead>
<tr>
<th>Site for data collection</th>
<th>Day care rehab</th>
<th>Stroke unit</th>
<th>Municipality A</th>
<th>Municipality B</th>
<th>Municipality C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study I</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study II</td>
<td>X</td>
<td>home care</td>
<td>rehab</td>
<td>SH</td>
<td>RH</td>
</tr>
<tr>
<td>Study III</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

SH: short-term care  
RH: residential home  
DC: dementia care unit

Samples

For the readability of this text, all patients will be referred to in the following as “he”.

Study I

Patient records, including discharge summaries, representing patients with a stroke diagnosis (n=106) and discharged from a stroke unit January to June 2003 were consecutively included. Of these 106 records, 59 (55.7%) contained one or more notes on eating difficulties and were selected for the sample.
Table IV. Characteristics of patients with eating difficulties discharged from hospital after stroke (n=59).

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Men (n= 27)</th>
<th>Women (n= 32)</th>
<th>Total (n= 59)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, years</td>
<td>78 (71-84)</td>
<td>82 (79-85)</td>
<td>80 (74-85)</td>
</tr>
<tr>
<td>Md (q1-q3)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Length of stay, days</td>
<td>27 (11-45)</td>
<td>29 (11-42)</td>
<td>27 (11-45)</td>
</tr>
<tr>
<td>Md (q1-q3)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discharge destination [n (%)]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home</td>
<td>12 (44.4)</td>
<td>12 (37.5)</td>
<td>24 (40.7)</td>
</tr>
<tr>
<td>Residential home care</td>
<td>15 (55.5)</td>
<td>20 (62.5)</td>
<td>35 (59.3)</td>
</tr>
</tbody>
</table>

Study II

A convenience sample of 16 triads was selected from a stroke unit from December 2007 to September 2008. One patient chose not to participate, resulting in a final sample of 15 triads. A triad consisted of one patient with stroke, his patient record and information in paper-based and electronic discharge summaries and the nursing staff (one registered and one assistant nurse) from the receiving residential home care unit. The following inclusion criteria were used: the patients should still have some eating difficulties at discharge; they should be discharged to care in one of the three municipalities; and they should be able to give informed consent, independently or with help from their next of kin. Inclusion criteria for the nurses were that they should be involved in the care of the actual patient and that they had not been interviewed before in the actual study.

The patients, six women and nine men, were old (mean 83 years, SD 6.9) and suffered from multiple problems that were caused by stroke and by other medical conditions. Thirteen patients had one or more additional cardiovascular diagnosis: one had diabetes and one had rheumatoid arthritis. All 15 registered nurses who participated in the study, except two, were women as were the 15 assistant nurses. Both registered and assistant nurses (10 registered and 7 assistant nurses) had been in their professions ≥ 15 years.
**Study III**

In January 2002, an assistant nurse and an occupational therapist at the day-care rehabilitation unit identified three participants as having eating difficulties according to their individual judgements. All three patients had been cared for in the stroke unit previously described (studies I and II) and had been discharged 1½ years earlier. The participants were:

A: a 68-year-old man with dysarthria that he could manage when he concentrated on speaking slowly and was well rested and calm;
B: a woman 82 years of age who had dysarthria, with a wet-sounding voice and frequent coughing when talking; and 
C: a 61-year-old man who had dysarthria with whispering, slurred speech.

**Study IV**

The experiences from study III, in addition to another qualitative study on experiences from persons with traumatic brain injury (TBI) (Paterson & Scott-Findlay, 2002), combined with an extensive literature review, were the bases for study IV. The communication impairments of the participants in both studies included expressive or receptive aphasia, paralysis leading to altered non-verbal communication, memory loss causing difficulties with recall and dysarthria causing muffled, slurred and weak speech.

**Data collection**

This thesis deals with written and verbal communication, with individuals’ experiences and perceptions and with representation of patient problems that have been identified and care that has been provided. Such a complex aim demands several methods for data collection.
Audit of patient records (Studies I and II)

Audit of patient records was chosen for data collection in order to retrospectively investigate how eating difficulties after stroke had been described, how eating-related multidisciplinary care had been planned and evaluated and how those difficulties had been described in discharge summaries. For study I, a protocol was developed based on two existing instruments for record audit (Ehnfors & Smedby, 1993; Thorell-Ekstrand & Björvell, 1995) and on two instruments for identifying eating difficulties after stroke (McLaren & Dickerson, 2000; Westergren et al., 2001b). The audit protocol contained 30 items covering demographic data (5 items), data about eating difficulties and related problems (16 items) and data on care planning (9 items). There was a mix of response alternatives (nominal and ordinal level) and for nine items text could be copied into the protocol. The quality of the care plan was rated on a 3-point scale with 1 denoting poor quality, 2 moderate quality and 3 adequate quality. The comprehensiveness of the discharge summary on patients’ condition, interventions and prevention related to eating difficulties and patients’ communicative ability was also rated on a 3-point scale. The protocol was pilot-tested, which led to the revision of five items.

In study II, record data were collected in a different way than study I. All text in the patient record and in the electronic information tool used for information transfer between hospital, primary health care and municipality care (here called ITT) that held information on the patients’ eating and nutrition was copied into a Word file for further analysis. Additionally, demographic data, medical diagnoses, length of stay and discharge destinations were collected.

Screening for nutritional risk and eating difficulties (Study II)

To obtain reliable information on the state of the participants that could be compared with the other data sources used in the study one instrument was used to screen for nutritional risk and another for eating difficulties. Both screenings were done a few days before discharge.

Mini Nutritional Assessment – Short Form (MNA-SF, Rubenstein et al., 2001) is a six-question screening tool developed from the more extensive Mini Nutritional Assessment (MNA) (Guigoz et al., 1994) to identify older persons at nutritional risk and provide information for planning of interventions. The six items describe food intake, weight loss, mobility, neuropsychological problems, psychological stress and body mass index (BMI). A score ≤ 12 indicates risk for
undernutrition (maximum score = 14). MNA and MNA-SF have been extensively tested for reliability and validity in European and Swedish populations (Rubenstein et al., 2001; Saletti et al., 2000).

Minimal Eating Observation Form (MEOF-I) is a screening instrument developed to detect eating difficulties, earlier described (p. 26). The instrument contains 11 dichotomised items organised in four categories indicating difficulties in ingestion (sitting position, manipulation of food on the plate, transport of food to the mouth), deglutition (open/close the mouth, manipulation of food in the mouth, swallowing), lack of energy (eats less than ¾ of normal portion, energy to complete a meal, time to complete a meal) and other eating difficulties (appetite, chewing/denture problems). In this study the category other eating difficulties was excluded and thus only 9 of the 11 items were used.

**Interviews (Studies II and III)**

Two interview methods have been used in this thesis with the purpose of describing individuals’ perceptions and experiences.

In study II, the interviews with registered nurses and assistant nurses were conducted as structured telephone interviews. Two weeks after discharge of the participating stroke patient the manager of the residential home care unit (and in one case the home care team) to which the patient was discharged selected one registered nurse and one assistant nurse to be asked for participation in the telephone interview. After receiving written and verbal information about the study and informed consent, all nurses agreed to take part in the interview that lasted 20-40 minutes. An interview protocol, containing 24 questions, was specifically designed for this study. Of those questions, 23 were multiple-choice items (nominal and ordinal level) with a possibility to add the respondent’s comments. The remaining question was open-ended: “Would you please describe this patient’s eating ability?” The questions covered demographic data (3 items), data on care organisation and responsibilities (7 items), the process of information transfer (5 items), perceived quality of transferred information (3 items), management of insufficient/lack of information from hospital (1 item) and knowledge in eating and nutrition (4 items). During the interviews, the answers were written by hand in the interview protocol (in some cases completed after the dialogue was finished).

In study III, the first interview was carried out approximately 1½ years after the participants’ discharge from the stroke unit. All interviews were tape-recorded. In a pilot interview we realised that it was difficult for the informants
to talk about their eating difficulties without associating to the care episode and the acute state of their stroke. Accordingly, to help the informants focus on the phenomenon we wanted to explore, the opening question was asked: “Do you remember when you were at hospital and first realised that you could not eat like before?” After that question was administered, it was easier for the informants to describe the current situation.

An interview guide was constructed based on earlier research (Axelsson et al., 1989; Jacobsson et al., 2000; Perry & McLaren, 2003a). The guide focuses on how eating was handled, experiences of situations and activities related to eating and meals and on expectations for the future related to eating and meal-related activities. All three informants had dysarthria in addition to their eating difficulties, which made it hard for them to express their thoughts in long sentences and rich narratives. The informants’ non-verbal communication, such as facial expression complementing a slurred and flat voice and short sentences, was observed and documented (Kvigne et al., 2002). The second interview had the purpose to provide a richer description and to confirm that the informants’ statements had been understood according to their point of view. That interview was conducted three months after the first one and on this latter occasion, the informant was invited to have a light meal. Observations of the meal situation were recorded in field notes during and immediately after the meal.

Methodological exploration and discussion (Study IV)

Study IV was based on lessons learned from two qualitative studies exploring the experiences of patients with communication impairment related to acquired brain damage. We started with a literature review in which 16 international textbooks on qualitative research methods used in Swedish PhD courses were reviewed. The focus was on design, sampling, vulnerable groups of informants and ethical issues. In addition, we searched for scientific papers in electronic databases (CINAHL, AMED, PsychINFO) and through personal contacts with researchers. A wide range of topics (patient experiences, communication in caring relations, patients’ responses to rehabilitation programmes, teaching and methodological issues) and key words (communication, communication disorders, speech disorders, aphasia, cognition, cognition disorders, language, qualitative studies, narrative, interviews, life experiences, phenomenology, brain injuries, traumatic brain injury, cerebro-vascular disorders, neurology, dementia, research ethics, research and research nursing) were combined in the search.

Empirical material (transcripts and field notes) and researchers’ experiences were drawn from two qualitative interview studies, the first being the
study on the experiences of living with eating difficulties after stroke (Study III) while the second study had its focus on the experience of survivors of TBI and their next of kin (Paterson & Scott-Findlay, 2002).

**Data analysis**

Data from studies I and II consisted of text from patient records, electronic discharge summaries and, additionally, in study II from structured telephone interviews. The texts were often short and “telegraphic” making the choice of content analysis appropriate for analysing the data.

In study I, we scrutinised the selected documents using the audit protocol to find descriptions of eating difficulties and related multidisciplinary care planning, interventions and evaluation. The audit of discharge summaries intended to capture completeness in the information transfer to residential home care in relation to what had been recorded about eating difficulties during the episode of care. All text concerning eating difficulties and nutrition was extracted from the records and categorised according to the items in the protocol. Because many notes were unspecific and written in lay language, the categorisation entailed elements of interpretation related to the stroke care context. During data analysis, the category ‘Other eating problems’ was intuitively further divided into six categories.

In study II, the procedure was somewhat different from that in study I. Text from the patient record and from ITT that had been extracted into a Word file and was subsequently analysed with content analysis using the audit protocol as a coding scheme (Krippendorff, 2004). To strengthen validity and reliability of the findings record data for three patients were analysed by a second reviewer, a registered nurse experienced in auditing records. The findings were discussed until agreement was reached in the interpretation of the text. Data that did not fit into the coding scheme were primarily coded as ”Additional eating-related problems”. During the analysis process that code was divided into eight categories. Data from the telephone interviews were analysed in two ways: frequencies of structured answers were analysed with descriptive statistics while the open-ended question was analysed using content analysis.

In study III, the interview situation itself was the start of the data analysis process (Kvigne, et al., 2002; Morse, 1994; Silverman, 2003) while attempting to have the informant clarify the meaning of what was said. This was especially important in that the informants’ speech was hard to understand. For the same reason, being open to the informants’ non-verbal communication was important.
All audio-taped interviews were transcribed verbatim promptly after the interviews. The transcription was an important part of the data analysis, with interpretation of what was said during the interviews continuing into this phase (Morse, 1994). During the first interview, some preliminary themes emerged from the informants’ stories, which were further elaborated in the second interview. The analysis procedure was inspired by the phenomenological tradition and can be described in five steps (Kvale, 1996): (a) naïve reading of the whole text and simultaneous listening to the tape-recorded interviews (b) extracting natural meaning units from the texts and key words from the observation notes; (c) formulating the statements that dominate the meaning units and observation notes into preliminary themes using the question, “What does it mean to live with eating difficulties after stroke?” (d) refining the preliminary themes by moving back and forth between the research question, the texts and the audio-tape until a more abstract expression of the theme is synthesised; and (e) bringing together the themes from the three informants and weaving together the central themes into a descriptive statement.

In study IV we used our experience from two qualitative research studies in which we interviewed persons who had experienced stroke and traumatic brain injury as the basis of the study. Data collection and data analysis used both inductive and deductive approaches in an intertwined process in which discussion and analysis led to new ideas for data collection: for example, when we identified many relevant studies for our purpose in research in the field of learning disabilities. Analysis was a process of scrutiny of our literature findings and our empirical material, of discussions with researchers that we identified during data collection and thorough discussions in the two research groups.

**Statistics**

Descriptive statistics were used in studies I and II to analyse demographic data, frequencies of recordings and telephone interviews.

**Reliability and validity**

Because this thesis consists of two quantitative studies, one qualitative and one methodological study, reliability and validity have to be handled in accordance with the different study designs.

In study I the audit protocol was pilot-tested with the consequence that five items required revision. Inter-rater agreement on the items in the final protocol was tested by having a second reviewer auditing 10% (6 records) of the
sample. Inter-rater agreement for all items ranged from 100% agreement on 17 items to 80–90% for 8 items, 70% on three items and 60% on two items. The κ-coefficient value for a random sample of 11 items ranged from moderate (κ= 0.41–0.60) for three items to very good (κ= 0.81–1.0) for eight items (Altman, 1991). As described earlier, another strategy was used in study II, where record data for 3 of the 15 patients were analysed by a second reviewer; the findings from this study were discussed until agreement was reached in the interpretation of the texts and the meaning of the codes. The interview protocol used in study II was pilot tested for clarity in interviews with two nurses who did not take part in the study, but the pilot results suggested no changes in the protocol were required.

In study III, which is a qualitative study, reliability and validity were matters of trustworthiness (Lincoln & Guba, 1985), or a process of continually checking, questioning and theoretically interpreting the findings (Kvale, 1995; Morse et al., 2002). Checking the findings or taking steps to improve credibility in this study included that careful attention was paid to ensure that the speech of the informants was properly understood. After formulating the first, preliminary themes, the informants were asked to verify that the investigator had understood their statements correctly. The informants also had an opportunity to elaborate on the emerging themes with the purpose of expanding the depth and validate the emerging analysis. All three authors took part in formulating the interview guide, listening to the audio-tapes, extracting meaning units and formulating themes. To improve transferability the description of the context and the observations was written as "thick" as possible (Lincoln & Guba, 1985). To improve confirmability data collection, interpretation of the data and preliminary findings were discussed at a national nursing conference workshop with expert researchers and nurses experienced in stroke care.
Ethical considerations

Planning research on older people with severe impairments, frequently aggravated by communication impairment, is a delicate matter. It demands an ethical stance, awareness of the problems that can occur when asking for informed consent and during data collection and a willingness to change the data collection process if participants are expressing discomfort or embarrassment. The three empirical studies of this thesis involved ethical challenges of varying degree: study I was based on recorded information on patients’ eating difficulties and study II entailed recorded information, assessment of patients’ eating ability and interviewing staff about patients’ eating. To ensure participant confidentiality no patient record or discharge summary was photocopied, data were transcribed and coded and no personal identification of patients was collected (I, II).

While the way people eat is something private, an activity that may involve feelings of shame, fear and embarrassment in the case of eating after stroke, assessment of a meal for research purposes has to be handled with great sensitivity (II). When screening for eating difficulties, the researcher had first planned to sit close to the observed patients, but chose after a pilot test to do the observation more discretely from a distance of approximately five meters. Despite this strategy, one patient declined to be observed during a meal. All of the participants in Study III had communication impairment in addition to their eating difficulties, stressing the importance of giving careful information about the study and to be sensitive to any signs that the informant wanted to withdraw from the interview. Persons with communication impairment are at risk of being dependent on the researcher because the interview exposes the individual’s experiences and feelings. Thus, the interview could develop into a quasi-therapeutic dialogue (Dickson-Swift et al., 2006). This risk must be handled with care and precautions must be taken to ensure that the informant is not left in a state of anxiety and without support if the need for debriefing arises. On the other hand, the interview might give these informants an opportunity to tell their story to someone who is genuinely interested in their experiences. Another aspect of interviewing persons with eating difficulties and communication impairment after stroke is the need for tactful handling of the embarrassment and the practical problems that are caused by drooling, coughing and uncontrolled crying that often accompany those stroke sequels. The investigator had extensive experience as a geriatric nurse and was familiar with communicating with persons with speech problems. The personnel at the day care unit (III) were informed about the study and were able to support the informants if they showed signs of
emotional distress after the interviews. One of the interviews had to be interrupted because the participant was displaying non-verbal and verbal signs of distress. During debriefing, however, he declined counselling and expressed relief that he had had the opportunity to talk about his experience during the interview.

Preparing a theoretical paper (IV) does not involve vulnerable people directly. However, the topic raised many ethical problems. An overriding impression was that the challenge of gaining access to the experiences of people with communication impairment has seldom been attended to in research methodological literature despite that this is a crucial ethical problem in qualitative research involving a large group of persons who have survived acquired brain damage with residual communication impairment.

The studies complied with the rules of the Helsinki Declaration (World Medical Association, 2000) and were approved by the research ethics committee, Örebro County Council.
SUMMARY OF THE RESULTS

Multidisciplinary stroke care for patients with eating difficulties as documented in the patient records and discharge summaries (Study I)

The content of information on patients’ eating difficulties varied considerably in the 59 patient records. In total, 358 notes on eating difficulties were found, with fifty-two (88%) records containing some sign of unsystematic screening for dysphagia at admission and at least one measurement of body weight. No comprehensive assessment based on established methods of nutritional status or eating ability was observed. Problem statements related to eating were mainly found in the nursing documentation and 78% of actual recording (n= 358 notes) were made by nurses while 13% were made by physicians. The most frequently represented category of eating difficulties was “Handling of food in the mouth and swallowing” (105 notes, 29%); other frequently occurring aspects of eating were “Fatigue/Lack of energy” (59 notes, 17%), “Appetite/Eats poorly” (54 notes, 15%) and “Nausea/Vomiting/Regurgitation of food” (48 notes, 13%). “Other eating problems” included six categories: “Assisted eating”, “Modified consistency diet”, “Denture/Oral problems”, “Neglect/Visual field loss”, “Rejects food” and "Nutritional problems/Enteral or parenteral feeding”.

The number of eating difficulties and nutritional problems described for a patient varied from one (5 records, 8.5%) to five (3 records, 5%). The majority of records (n=52, 88%), however, had only notes on the patients’ current problems, often lacking professional description and with few signs of planned or performed interventions, goals and outcomes. Of three patients who each had five eating difficulties recorded, no one had notes on multidisciplinary care for their extensive and complex eating problems. Most records contained coherent but unstructured multidisciplinary care plans for many physical functions, except for eating. Forty-seven (80%) of the 59 multidisciplinary patient records contained discharge summaries, including some degree of care planning, whereof 36 (77%) held information on the patients’ eating ability. Generally, discharge summaries were lacking comprehensiveness and care plans showed unsatisfactory quality in 21 (45%) records, moderate in 24 (51%) and adequate in 2 (4%). Individual goals and need for nutritional support or assistive devices related to eating were absent in the discharge summaries.

In summary, various eating difficulties were documented in all the patient records but with few signs of multidisciplinary collaboration related to eating
difficulties. As represented in the patient records, unsystematic screening for dysphagia was routine praxis while other aspects of nutritional care (such as screening for nutritional risk and eating difficulties) were lacking. Multidisciplinary discharge summaries were of low quality and entailed little information on patients’ eating ability.

**Accuracy of information about eating difficulties in stroke patients discharged to residential home care (Study II)**

The MEOF-I and MNA-SF instruments were used by the investigator for independent description of each of the 15 patients’ eating difficulties and for describing their risk for undernutrition. As in study I, no documentation of screening for nutritional risk or eating difficulties was found and few signs of planning and evaluation of eating-related care appeared in the records. The patients’ problems were described in lay-language and in an unspecific way. Moreover, accuracy was inadequate with several aspects of eating difficulties missing when compared with the systematic observation of patients’ status. The two aspects of eating difficulties most frequently documented were difficulties with swallowing and lack of energy to complete a meal. At discharge, all patients but one had difficulties with manipulation of food on the plate, whereas all patients had deglutition difficulties with swallowing and manipulation of food in the mouth and 13 had difficulties in one or more aspect of lack of energy. The ITT held information on eating difficulties with varying degrees of comprehensiveness for 11 of the 15 patients, but coordinated care planning related to those extensive eating difficulties was largely lacking in the documentation.

**Accuracy of eating-related information transferred at discharge as perceived by registered and assistant nurses in residential home care (Study II)**

As reported by registered and assistant nurses two weeks after discharge from hospital, for some of the residents the situation differed from how it was described in their discharge summaries. Four residents had oral problems including candidosis that was not recognised in their patient record or discharge summary. One had earlier unrecognised visual impairment that complicated mealtime activities. Four residents had better eating ability than was expected
from the information transferred. According to the nursing staff, two residents expressed that they did not want to eat, which was not recognised in the discharge summaries. The assistant nurses had identified eating difficulties in seven of the nine items, whereas registered nurses had identified difficulties in four items. Both registered and assistant nurses expressed that they were used to making their own judgements about new residents’ functions and problems in addition to the information transferred from hospital. They also pointed out that they often used information from the resident and next of kin. In the telephone interviews the 15 registered and 15 assistant nurses were asked to appraise the information transferred from hospital in the categories “sufficient”, ”fair but some information missing”, ”insufficient”, ”no information” and ”wrong information”. The nurses’ perceptions of transferred information are presented in Table III.

Table V. Accuracy of information transferred to municipal care as perceived by registered nurses and assistant nurses (n = 30).

<table>
<thead>
<tr>
<th>Variables</th>
<th>Registered nurses</th>
<th>Assistant nurses</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sufficient</td>
<td>5</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Fair, but some information missing</td>
<td>5</td>
<td>7</td>
<td>12</td>
</tr>
<tr>
<td>Insufficient information</td>
<td>3</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>No information</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Wrong information</td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Don’t know</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>15</td>
<td>15</td>
<td>30</td>
</tr>
</tbody>
</table>

Experiences of living with stroke and eating difficulties 1½ years after the stroke (Study III)

The way persons with stroke experienced living with eating difficulties was represented in one major theme and three sub-themes. The overall theme Striving to live a normal life comprised the sub-themes Abandoned to learn on one’s own, Experiencing losses and Feeling dependent. The process of getting back to a life that resembled life before the stroke or a new kind of “normalised life”, was experienced as a long-lasting process that required exceptionally hard work.
The first sub-theme, Abandoned to learn on one’s own, comprised expressions of being largely left on one’s own to learn a new way of eating and of handling mealtime situations and adjusting to a new life situation. Furthermore, the informants experienced a lack of adequate knowledge among the nursing staff they had met in the hospital, concerning how to help them with their eating difficulties. After 1½ years, the informants could eat almost everything they wanted and used no assistive devices in the meal situation. Even so, they expressed a strong wish to be able to eat in the way they did before the stroke. Concentration was vital for management of the bolus in the mouth and for swallowing safely and the fear of choking when swallowing that they had experienced in the acute phase of stroke had successively faded.

The second sub-theme was Experiencing losses. Two kinds of losses that informants described were related to eating difficulties: loss of functional eating ability and loss of the ability to perform valued activities related to food and meals. Loss of bodily functions ranged from the panic that one of the informants experienced when he realised that he could not swallow in the acute phase of his hospital stay, to experiences of hemi-paresis, severely decreased sensitivity in mouth and hand, difficulties in chewing and handling food in the mouth and loss of speech. Feeling dependent was the third sub-theme. In mealtime situations all three informants were dependent on others. This was partly due to their hemi-paresis and partly to a lack of home adjustment that would have enabled cooking and other food-related activities. After stroke, the mealtime situation became replete with new problems, including coughing, spilling, dribbling and not being able to handle food properly on the plate or in the mouth according to what was culturally acceptable to the informants. Another aspect of dependency was being dependent on social services for rehabilitation, home adjustment and personal assistance. Speech impairment was described as the most difficult disability to cope with.

Methodological aspects of sampling, informed consent and fatigue in informants with eating difficulties after stroke (Study IV)

Sampling for interview studies involving participants who have survived a stroke needs to be carefully planned if the researcher intends to investigate experiences from those persons whose stroke resulted in communication impairment. In the context of investigating experiences of aphasia, Parr and colleagues have invited persons with such impairment to be involved in developing research strategies that enable persons severely impaired by aphasia to participate (Parr et al., 1997). Ethnographic and case study methodology have successfully been used to capture
such experiences (Davidson et al., 2007; Parr, 2007). A few studies were found involving people with communication impairments in which the researchers had assessed potential participants’ communicative and/or cognitive ability during recruitment (for example, Perry & McLaren, 2003a; Young & Chesson, 2006). Assessing an individual’s cognitive capacity in the process of obtaining volunteers for a research study is often a delicate matter.

To obtain valid informed consent from persons with communication impairment for participation in a research study strategies and techniques used in the field of learning disabilities and aphasiology, such as Augmentative and Alternative Communication (AAC) (Beukelman & Mirenda, 1998), should be tested. AAC refers to ways, other than speech, that are used to communicate between persons, including gestures, writing and a variety of AAC devices ranging from simple picture boards to complicated digitalised speech devices. Various AAC devices have been used in studies with communicatively impaired persons (Killick & Allan, 2001; Murphy, 2000; Murphy, et al., 2005) and to present information for informed consent to participants (Jimison et al., 1998). Because they are required to recall painful or stressful occurrences in their illness or disability experience, interviewing people with communication impairment might cause them to experience distress (Philpin et al., 2005). The consent form for research involving people with communication impairment should state clearly that fatigue and discomfort are common during such interviews and that they should tell the researcher when they need a break or if they wish for the interview to be continued at a later date.

The fatigue that results for many people with communication impairments in interviews can cause the person to misinterpret the researcher’s questions (Finlay & Lyons, 2002) and provide responses that are incomplete or block the flow of their narrative (Bloch & Singh, 1999; Johnson, et al., 1993; Moyle, 2002). Other fatigue-related problems can be increasing speech problems, such as slurred and weakening voice and increasing monosyllabic speech. The implication of this is that when interviewing persons with communication impairment researchers should use shorter interviews than are typical.
GENERAL DISCUSSION

The ambition of this thesis is to describe how health care professionals in a specialised unit for stroke care documented information on eating difficulties in the patient record and what kinds of eating-related information were transferred to the nursing staffs in residential home care. To complement that professional perspective, a further ambition is to explore experiences from persons who had lived with eating difficulties for a period of more than one year, as well as possible research strategies to gain access to the experiences of patients who have eating difficulties in combination with communication impairment.

The results can be summarised as follows: Although several patients were at severe risk for undernutrition and had extensive eating difficulties, these problems were not systematically identified and were often not recognised in the documentation in patient records. Few signs of multidisciplinary collaboration on eating-related care were found in the patient records. Informational continuity in the transfer from hospital to residential home care was insufficient for most patients when it came to eating difficulties and nutritional care. Persons who had experienced a stroke and still had eating difficulties more than one year after their stroke, expressed a strong wish to eat in the same way as they did before the stroke event, even though they had to manage multiple and severe eating difficulties such as dysphagia in the mealtime situation. They also expressed feelings of being largely left on their own to learn and adjust to a new way of eating, as well as feelings of loss in the sense that they lacked the ability to carry out appreciated food-related activities. To be able to include persons in qualitative studies that have experienced a stroke and that have eating difficulties, often aggravated by communication impairment, researchers need to develop creative, participatory approaches. The present findings will be discussed relative to these statements. First, however, it is necessary to reflect on what knowledge can be retrieved from patient records, and how well such record data can be assumed to represent patients' total care episode.

Representation of nutritional care in patient records

In the first part of this thesis (I, II), the focus is on written communication, which is obviously only one aspect of communication about patients in stroke care. However, the multidisciplinary patient record and the discharge summary are important tools for continuity of care, where high quality documentation is an essential component of patient safety, holding permanent and unchanged information (Kripalani et al., 2007; Witherington et al., 2008). Documentation in
the patient record is ideally the representation of health care professionals’ clinical reasoning, judgements and priorities, as well as the care that has been planned, and the care that has been provided and evaluated. Clinical reasoning has been defined as “the thinking and decision making processes which are integral to clinical practice” (Higgs & Jones, 2000, p. xiv), characterised by two core features (the role of clinical knowledge, and the dependence on context). In this thesis a central aspect of clinical knowledge concerns how to manage the patients’ nutrition and eating difficulties. The contextual aspect of stroke unit care could be interpreted as being manifested in patient records when nurses documented, for example, the patients’ need for modified food consistency without reference to the causes of such a need. Registered nurses were those professionals that made the majority of notes on eating difficulties and nutritional matters, documented in a format with keywords adhering to the commonly used Swedish VIPS model for nursing documentation (Ehrenberg et al., 1996), but with unstructured notes and without summarising the patients’ problems into nursing diagnoses or explicit care plans. Registered nurses are those professionals spending 24 hours a day at the ward, often in close contact with the patients. Accordingly, much information on patients’ eating and nutritional needs might be kept only in the memories of the nurses. Other studies investigating registered nurses’ documentation in the patient record have reported low quality recording on nutritional care for stroke patients in nursing homes (Kumlien & Axelsson, 2002), for patients in various specialties in an acute hospital (Perry, 1997) and for patients in cardiac care (Adamsen & Tewes, 2000). In a recent study on nurses and nurse managers’ perceptions on nutritional assessment and documentation, Persenius and colleagues (2008) concluded that important nutritional documentation was missing despite the nurses’ recognition of undernourished patients in their wards.

Lack of professional and consistent terminology was revealed in the documentation with patient status and interventions expressed in a vague and unspecific lay language. The use of the MEOF-I items could be one way to verbalise patients’ eating difficulties in a more systematic and professional way than what was observed in our studies. To provide continuity of care for patients with stroke and eating difficulties discharged to residential home care facilities the content of discharge summaries has to be comprehensive, describing all essential aspects of patients’ functioning and needs.

If documentation in the patient record reflects health care professionals’ knowledge on nutrition and eating difficulties, these stroke experts’ knowledge seems insufficient (I, II). This same knowledge was also found to be deficient
among the nursing staff in the participating residential home care units. Even if important risk factors for undernutrition were recorded (for example, repeated nursing documentation on reduced body weight), the records rarely showed evidence that these factors were integrated into a care plan or transferred in its entirety. This lack of knowledge has been reported in several studies (Lobo et al., 2001; Mowe et al., 2008; Persenius et al., 2008). In addition, little interest has been shown among health care professionals in nutrition and meal-related matters (Mowes et al., 2006; Bachrach-Lindström et al., 2007). As interpreted from the documentation and the interviews with nurses, eating difficulties after stroke appeared to be perceived as a normal and everyday condition. According to the interviews with persons who had such difficulties (III), and from the research of Jacobsson and colleagues (2000b), these difficulties, however, were experienced as frightening and shameful in the acute phase of stroke. Further, after the acute phase, individuals expressed shame and embarrassment over their appearance (III). As Sidenvall and collaborators reported earlier (Sidenvall et al., 1994; 1996; 1999), older patients have a desire to behave in accordance with established table manners while meeting ward culture, where institutional routines normally take preference over the individual’s autonomy. The older patients experienced reduced well-being at mealtime because of the cultural conflict between their personal norms and those of the institution. In our study (III) we also found little support from the nursing staff on how to learn new ways of eating after stroke adapted to the patients’ individual difficulties. This cultural conflict was evident when screening patients’ eating difficulties during an ordinary meal in the stroke unit (II). In the recent National Swedish guidelines for stroke care (Socialstyrelsen, 2005) advice on relevant nursing interventions related to eating difficulties was presented. At the time of data collection of study I in 2003, those guidelines were not published, whereas at the time of study II, which was performed in 2007–2008, it is reasonable to require that the guidelines had been implemented two years after its publication. However, we could find no evidence that these guidelines were used in the stroke unit under study.

Assessment of patients’ eating-related functions

Another compelling finding in this thesis is the absence of documented assessments of eating-related functions despite (1) guidelines mandating such assessments, (2) researchers emphasising that such systematic investigations are important prerequisites in providing patient safety and (3) that non-structured assessments could result in important information being neglected (Jensdóttir
et al., 2008; Persenius et al., 2008). Much of the documentation can be assumed to have been based on more or less explicit assessments and dependent on the stroke care context, though not documented: for instance, when nurses wrote, “Patient eats better”, that could be understood by the stroke team members as implying that the patient had a better appetite than previously. If so, the note could be interpreted as a very rough evaluation of care provided even though it was impossible to recognise what intervention caused the improvement in eating.

While the impact of intuition has been emphasised in expert nurses’ clinical reasoning (Benner & Tanner, 1987) and described as a product of knowledge, expertise and experience (Effcen, 2001), systematically assessing the patient has also been emphasised as an important aspect of data collection for clinical judgements. In addition, instruments for screening and assessment are valuable in the collection of clinical data. The call for evidence-based practice mandates systematic assessments and knowledge-based interventions. Assessment in health care is a broad concept, which this thesis has not explored. However, in her thesis, Törnquist (1995), studying occupational therapists’ assessment of activities of daily living (ADL), presented a structure of assessments that can be useful in interpreting our findings. She concluded that unsystematic assessments held multiple shades of meaning but with less exactness and with inconsistent terminology as compared with systematic assessments. The author further asserted that the actual situation and practical circumstances were more important than reflections based on a theoretical framework when occupational therapists assessed ADL function in patients with stroke and other medical diagnoses. Three categories of assessment were identified: assessment only, process-focused assessment and intervention-focused assessment. Based on Hasenfeld’s theory of human service organisations (1983), Törnquist characterised the purpose of assessment only as identifying and “labelling” patients for transfer to another care provider: for example, the label “stroke diagnosis” (people-processing technologies, according to Hasenfeld). Process-focused assessment had the purpose of contributing to a change in the patients’ state or attributes: for example, to improve the patients’ perceived capacity for training (people-changing technologies). The third category, Intervention-focused assessment often omitted examination and put focus directly on how to solve the problem, which formulated patients’ problems through interventions (people-sustaining technologies). In this thesis much of the documentation on eating difficulties could be categorised as intervention-focused assessment. Further, when nurses described the patients’ eating difficulties in the interviews, they often
Informational continuity of care

Failure to transfer accurate, complete and up-to-date information across interfaces in care represents a major, avoidable, risk to patient safety (Witherington et al., 2008). From a nutritional perspective, patient safety concerns identifying patients at risk for undernutrition and acting to reduce nutritional decline. Recently, Constantinou and Jenkins (2008) emphasised the need for explicit management of nutritional care and that nutritional care is a central component of continuity of care. Despite that discharge summaries were sent to residential home care units at discharge for most patients with eating difficulties, there did not appear to be consensus on what types of eating-related information were important to transfer (I, II). No information was found on care planning for the patients, what kind of nursing interventions or support in mealtime situations the patients needed, as well as, no information on nutritional requirements. Rather, only information on intervention-focused statements, such as “Patient needs assistance to eat”, could be found. Similar experiences were reported by Hellesø (2006) who found unspecific discharge notes on patients’ appetite (i.e. patients’ status) in Norwegian health care. She suggested that nurses assumed that colleagues in residential home care facilities would know what these statements implied.

Nurses in residential home care units conveyed that they always received telephone handover from nurses in hospital at time of discharge. Another component of informational continuity that was not studied is the care planning conference. However, our results show that, whether various forms of verbal information had been transferred or not, neither registered nor assistant nurses were completely satisfied with the information they had received on eating difficulties. For assistant nurses, the lack of information transfer was obvious, and to our knowledge, studies on what discharge information reaches assistant nurses in residential home care has not been reported earlier. However, memory can be unreliable and it is important to recognise that the interviews with nurses were made two weeks after discharge of the actual patient.
To live with eating difficulties one year after stroke

The persons participating in Study III described how they had struggled to deal with their severe eating difficulties. Two of these individuals had experienced feeding via PEG or surgical gastrostomy during the first six months after discharge. Despite their severe impairment with multiple additional manifestations of stroke, all three participants expressed that meals and mealtime activities were important to them and that they had learnt to manage eating their favourite dishes though with different tricks that they had discovered through trial and error. The participants’ descriptions of how they had to handle this learning process without support from health care professionals points to a major deficiency in the continuous stroke care delivery system. This can be added to the previously described lack of nutritional knowledge and the ward culture which implies that health care professionals and patients have different perceptions of what is essential in mealtime situations, and perhaps on the importance of the meal as a socio-cultural phenomenon. However, the sample came from one geographical area, where the patients had all been cared for in the same hospital during approximately the same time. The findings were the experiences of those persons. However, it is reasonable to think that because nutritional knowledge has been shown to be lacking among health care professionals in general, this might also reflect the experience that persons with stroke have of the general inability of professionals to support them when it comes to learning new eating strategies.

One finding that was surprising, was the lack of housing adjustment in the kitchens that was expressed by all three participants. It appeared as if these persons were not assumed to be interested or able to perform meal-related activities; for instance, one of the participants described how he had tried to make municipality authorities change the decision not to provide adjustment of his kitchen. Instead he had received Meals-on Wheels (programmes that deliver meals to individuals at home who are unable to purchase or prepare their own meals).

Knowledge about the experiences of persons living with eating difficulties after stroke is essential for the development and provision of good nursing care for that large population. All the participants in study III expressed a fear of not being understood by the interviewer. The purpose of study IV was to discuss methodological issues in qualitative interviews involving people with communication impairment after acquired brain damage such as stroke. However, other research methods than interviews (for example, ethnographic, Parr, 1997, or life history research using autobiographic texts, Goodson, 2001) might be used to
explore experiences of persons with communication problems. Such research needs to be based on creative approaches involving persons who have communication impairment. Moreover, if the research involves interviewing persons with communication impairment, the interviewer probably needs to be trained in such communication to be able to adjust data collection methods to the type of communication problems that these individuals experience. Some researchers have proposed the use of AAC (for example, pictures and symbols) in such research (Lewis & Porter, 2004). Future research should investigate how approaches used in aphasiology and learning disability research (Dockrell, 2004) might be adapted to studies of persons with eating difficulties and communication impairment. One design for interview studies that has appeared in research reports lately is the use of the Internet (Adams et al., 2005; Piamjariyakul et al., 2006). For example, persons with dysarthria might benefit from such a data collection approach. However, health care researchers hold different perceptions on the advantages and disadvantages of using this medium (Hamilton & Bowers, 2006; Kralik et al., 2006). Thus, Internet interviews cannot replace verbal dialogue without considering these advantages and disadvantages.

One of the aims of study IV was to explore how to deal with the problem of fatigue when interviewing persons with a brain damage and communication impairment. Fatigue is a common symptom in many persons who have suffered from stroke. Fatigue is a complex concept, and, not surprisingly, a multitude of definitions exist, where the boundary between normal and pathological fatigue is not clear (Staub & Bogousslavsky, 2001). One definition is that fatigue is a feeling of early exhaustion, weariness and aversion to effort (van der Werf et al., 1998). In our study fatigue was defined as exhaustion that develops in connection with activities requiring effort, without reference to depression or psychological fatigue.
METHODOLOGICAL REFLECTIONS

The research questions in this thesis led to the use of a complementary approach that used both quantitative and qualitative strategies with the purpose to integrate different aspects of the phenomenon under study (Hammersley, 1996). In two of the studies record audits were chosen to collect data (I, II). Caution must be exercised when patient records are used as evidence of care delivered and of information transferred. In Swedish nursing and occupational therapy there is a strong tradition of transferring information verbally at discharge to colleagues in residential home care. Obviously, that information cannot be captured by auditing the records and was not aimed for in our study.

The accuracy of recorded data has not been studied extensively, which may result in uncertainty on data validity. Two complementary perspectives have been proposed to capture accuracy in record audits: "correctness" (the proportion of documentation that is in agreement with the actual circumstances) and "completeness" (the proportion of observations and planning that is documented) (Ehrenberg & Ehnfors, 2001). In this thesis we studied completeness in study I and described correctness (accuracy), and to some degree, completeness in study II. The audit protocol used in study I was composed of items from two existing instruments for record audits, complemented with items from two instruments for screening of eating difficulties. Inter-rater agreement was analysed using the kappa statistic. The kappa values for a random sample of 11 items ranged from moderate ($\kappa = 0.41-0.60$) for three items to very good ($\kappa = 0.81-1.0$) for eight items (Altman, 1991). The audit protocol in study II was further developed based on the research questions, and items not relevant for the study were excluded. In study II, the protocol was used as a coding scheme when analysing text from the patient records and structured interviews. Agreement or reliability was sought in that study, having the same Master student nurse as in study I coding data from three patient records. After that, we discussed our coding and interpretation of the data as well as face validity of the items until consensus was reached.

In addition, because of my considerable experience as a geriatric nurse, risk for bias was easily recognised. This experience might have resulted in positive interpretations of vague statements in the records that a researcher with another background would not have deduced. Therefore, additional to checking coding and inter-rater agreement, the data and the manuscript were processed by all three authors and discussed at multi-professional research seminars. Patient record data represented the entire hospital care episode, sometimes extending over several weeks. Screening of eating ability was conducted close to discharge in
order to represent the state of the patient at the time for discharge. Finally, the interviews were performed two weeks after discharge of the patients. Accordingly, eating difficulties described in the patient record, could have declined at the time of discharge, but it would still be relevant to include in order to predict nutritional risk in the discharge summary. The possibility exists that the problems that went unrecognised in the patient record but described by nurses in the municipalities could have developed during the one to two weeks after discharge. However, this is not likely because visual impairment and problems with chewing are persistent, appearing either much earlier in the illness trajectory or taking some time to develop.

A final reflection on these two studies (I, II) based on record audits is that the samples in both studies were not so large. The sample in study I was a consecutive sample of all records from a period of six months, which was judged to result in a sufficient sample. Study II used a limited sample of 15 triads because of the complex data collection process with its scheduled time sequences for gathering all data. To further study information management in continuous stroke care, the needed next step is maybe not to perform larger record audit-based studies, but to plan for more mixed-methods studies including, screening for eating difficulties, observation of care planning conferences and telephone handovers, complemented by interviews with nurses, in addition to record audits.

The choice to interview persons who had experienced eating difficulties for more than a year in study III, was based on two facts: (1) we presumed that the acute crisis phase was over and that the persons were in a more stable phase after their stroke and (2) we had found no study examining the experiences of living with eating difficulties for so long time after the stroke. Study III is one of the very few studies appearing in the literature, which attempts to describe eating difficulties in persons who have returned to their homes, or moved to a residential home after stroke. All informants had extensive speech problems in addition to their eating difficulties, which call for a creative approach to data collection. These speech problems can also have been a threat to trustworthiness since the speech of the informants was hard to understand. However, a combination of efforts to get to know the informants, repeated interviews and participant observations seems to be a useful strategy for data collection. Despite repeated interviews, the informants’ stories were not very rich in information. Another strategy for data collection could have been video-recordings combined with interviews. Video-recording of vulnerable persons, however, raises many ethical questions, and was, therefore, rejected.
The challenge to involve persons with communication impairment in qualitative research resulted in fruitful collaboration with a Canadian research group that also experienced similar challenges in interviewing people with traumatic brain injury. This collaboration resulted in study IV. We have stated that when studying experiences of living with eating difficulties after stroke, it is important to use creative strategies that will allow the inclusion of persons with communication impairment. Furthermore, researchers need to be knowledgeable in neuropsychology and communication methods suitable for persons with speech impairment.
PERSONS WHO HAVE EXPERIENCED A STROKE WITH RESULTING EATING DIFFICULTIES CONSTITUTE A LARGE GROUP OF OLDER PATIENTS IN CONTINUOUS CARE, MANAGED BY SEVERAL CARE PROVIDERS. TO USE VALID, RELIABLE AND EASY-TO-USE INSTRUMENTS IN IDENTIFYING EATING DIFFICULTIES AND NUTRITIONAL RISK IN THE ACUTE PHASE OF STROKE, MUST BE GIVEN PRIORITY BY THE MULTIDISCIPLINARY STROKE TEAM. HOWEVER, EVIDENCE-BASED INTERVENTIONS THAT CAN PREVENT NUTRITIONAL DECLINE AND RELATED COMPLICATIONS MUST ALSO BE GIVEN HIGH PRECEDENCE. MOREOVER, EATING DIFFICULTIES AND NUTRITION MUST BE STRESSED IN SUBSEQUENT REHABILITATION AND RESIDENTIAL HOME CARE SETTINGS. THE MNA-SF AND MEOF-I INSTRUMENTS ARE SUITABLE FOR SUCH SCREENING. TO PROVIDE HIGH QUALITY AND SAFE CARE THAT ADHERES TO NATIONAL GUIDELINES FOR STROKE CARE DOCUMENTATION OF EATING-RELATED CARE MUST USE STANDARDISED TERMINOLOGY. STANDARDISED TERMINOLOGY, WHICH COULD PROVIDE UNAMBIGUOUS INFORMATION IN FORMULATING NURSING DIAGNOSES AND CARE PLANS IN THE AREA OF EATING DIFFICULTIES COULD BE DEVELOPED FROM THE MEOF-I ITEMS. IF DEVELOPED TO HOLD A SUITABLE STRUCTURE, THE ELECTRONIC INFORMATION TRANSFER TOOL USED BY CARE PROVIDERS IN STUDY II COULD PROVE TO BE A RELIABLE COMPONENT IN INFORMATIONAL CONTINUITY. HOWEVER, NO MATTER HOW COMPREHENSIVE AND VALID THE INFORMATION IS IN THAT TOOL, THIS INFORMATION HAS TO BE READ BY NURSES AND OTHER HEALTH CARE PROFESSIONALS RESPONSIBLE FOR PATIENTS' CARE.

LITTLE KNOWLEDGE EXISTS ON EXPERIENCES OF LIVING WITH EATING DIFFICULTIES AFTER STROKE; IN FACT AFTER THE ACUTE PHASE AND THE INITIAL REHABILITATION PHASE OF STROKE SUCH KNOWLEDGE IS ALMOST NON-EXISTENT. STUDY III POINTED OUT SEVERAL ASPECTS OF THE PHENOMENON THAT SHOULD BE OF IMPORTANCE WHEN PLANNING LONG-TERM SUPPORT FOR THOSE PERSONS IN THEIR OWN HOMES OR IN A RESIDENTIAL HOME CARE SETTING. ONE ASPECT IS THE IMPORTANCE OF GETTING BACK TO NORMAL EATING, THAT IS TO EAT IN ABOUT THE SAME WAY THEY DID BEFORE THE STROKE EVENT. ANOTHER ASPECT IS THE NEED FOR HEALTH CARE PROFESSIONALS TO ACQUIRE KNOWLEDGE ON HOW TO SUPPORT PATIENTS IN THEIR EFFORT TO REGAIN EATING ABILITY THAT WAS EXPRESSED BY THE INFORMANTS. A THIRD ASPECT IS THE IMPORTANCE OF PROVIDING AN INSTITUTIONAL MEALTIME ENVIRONMENT IN HOSPITALS AND RESIDENTIAL HOME CARE FACILITIES THAT IS DESIRABLE FOR OLDER PERSONS WITH EATING DIFFICULTIES. THESE THREE ASPECTS CONSTITUTE THE FUNDAMENTALS OF A CULTURE THAT CAN SUPPORT PERSONS WITH EATING DIFFICULTIES AFTER STROKE SO THEY CAN MORE READILY ADJUST TO A NEW WAY OF EATING BASED ON THEIR INDIVIDUAL PREFERENCES AND HABITS.
This thesis has focused on two important aspects of stroke care that have not been studied in the past to any great extent: (1) Documentation and information transfer in continuous stroke care: in order to gain in-depth knowledge about the information transfer process from hospital to a residential home care facility, individual patients’ transition processes need to be studied (for example using case study methodology). Standardised terminology developed from the MEOF items, or from a multidisciplinary classification such as the International Classification of Functioning, Disability and Health (ICF) should also be studied. (2) It is essential to continue qualitative studies on experiences of living with eating difficulties after stroke. While those difficulties are often complemented by communication impairment, a study using a participatory approach to have persons who themselves have experienced such difficulties, participating in planning to help researchers find suitable methods to include those informants who are commonly excluded, would be an important way of developing qualitative methods for this large group.
CONCLUSIONS

This thesis has reported surprising deficiencies in identifying and recording stroke patients’ nutritional risks and eating difficulties. In addition, continuity of care for patients with eating difficulties after stroke was insufficient with poor accuracy and lack of comprehensiveness of the transferred information. To improve upon these deficiencies, the Swedish national quality register (Riks-Stroke) should include nutritional quality indicators such as screening for nutritional risk and eating difficulties. The following conclusions are drawn:

- Eating difficulties and nutritional risk were not systematically identified, but some kind of unsystematic screening pertaining to swallowing difficulties appeared to be routine at admission to hospital care.

- While multidisciplinary collaboration was evident in other areas of stroke care, signs of this form of teamwork was almost absent in the patient record with regards to eating difficulties and nutritional deficits.

- Concerning eating difficulties, informational continuity was insufficient for most patients. Nursing staffs in the residential home care facilities described that they made their own assessments of their residents’ eating abilities because information transferred from hospital at discharge was not always accurate.

- Persons, who still had eating difficulties more than a year after their stroke, expressed a strong desire to eat as they did before the stroke event, even though they had to manage multiple and severe eating difficulties. They also expressed a loss in the ability to perform appreciated food and meal-related activities. Finally, they expressed that they were not receiving adequate support in the area of housing adjustment, particularly with respect to daily food and meal-related activities.

- These same persons with eating difficulties more than a year after stroke described that they had handled adjusting to, and re-learning to eat in a new “normalized” way, receiving little support from health care professionals. Furthermore, these persons experienced that the health care professionals lacked knowledge in these matters.

- To study individuals’ experiences of living with eating difficulties after stroke important areas in qualitative research such as sampling, providing informed consent and handling informants’ fatigue during the interviews have to be acknowledged and methods have to be developed. In addition, researchers need to acknowledge that the experiences of persons with additional communication impairment are important.
TACK! (ACKNOWLEDGEMENTS)

Min forskarutbildning har varit en sju år lång resa på en bitvis krokig väg. En resa som innehållit utmaningar och glädjeämnen, svårigheter och stora förändringar. En resa där resenären (jag) har fått förmånen och problemet att dela uppmärksamheten mellan forskningsresan och ”livet därute” som ledare inom häls- och sjukvården. Det är många som har följt mig på vägen, som har gett förutsättningar för resan, som har stöttat, handlett, uppmuntrat och visat mig en helt ny värld.

Tack till min arbetsgivare, Örebro läns landsting och Lindesbergs lasarett, till dig Marianne Skinnars-Bruno som gett mig ekonomiska förutsättningar att bedriva forskarutbildning, till Jens Schollin i din gamla roll som forskningschef i landstinget och till Margareta Möller som chef för VFC, ert stöd har betytt mycket för mig. Tack också till Strokeförbundet, Vårdförbundet och Nutritionsnätet som bidragit till att finansiera mina studier.

Tack till personalen på strokeenheten, Lindesbergs lasarett som hjälpt mig med datainsamling, till alla de sjuksköterskor ochundersköterskor i Lindesbergs, Ljusnarsbergs och Hällefors kommuner som tålmodigt besvarat mina frågor – och naturligtvis till er som trots sjukdom ville medverka i mina studier.

Stort och varmt tack till mina båda handledare: Margareta Ehnfors som var min huvudhandledare under de första åren. Som lockade in mig på omvårdnadsinformatikens spännande område och så småningom på forskarutbildningen, som tog mig med ut i världen och introducerade mig för alla de stora forskarna inom Nursing Informatics. Och du Anna Ehrenberg, som tog över som min huvudhandledare, och med din klokhet och ditt metodiska arbetssätt många gånger hejdat mig och påmint: ”Vad var din forskningsfråga?”. Båda har ni tålmodigt hängt med på min resa; satt er in i teorier om kommunikation med personer som har nedsatt kommunikationsförmåga och teorier om ätande – och generöst delat med er av kunskap, hem och forskarnätverk. Vi har delat hotellrum och upplevt nya miljöer i Canada, Korea och Island, knutit internationella forskarkontakter och haft mycket roligt!

Ann Langius-Ekström, du efterträdde Margareta som professor – tack för ditt stöd.

To Professor Susan Grobe – Thank you for important discussions, reflections on my work, and for you support.

To Professor Barbara Paterson and Dr Shannon Scott-Findlay, our co-authors of paper IV – Thank you for instructive collaboration, preparing our paper was an exciting journey.
To Moira Calder and Leslie Shaps – Thank you for excellent language review.
Tack Anna Sand som var min medbedömare i två av studierna, som är en god vän och en kommande ”Informatics-syster”. Och till dig Arne Karlsson för all hjälp med format, fonter och marginaler.
Tack till alla kollegor på forskarutbildningen vid Hälsoakademin, Örebro universitet, för många spännande, utmanande och lærorika seminarier, och roliga fester. Ett särskilt tack till alla er, doktorander och lektorer i ”arbetsterapi-korridoren”. Ni har gett mig många nya infallsvinklar och ibland ifrågasatt omvårdnadsperspektivet, fått mig att inse vikten av aktivitet.
Varmt tack till Sigrid Odencrants – vi har delats glädje, stress och sorg under forskarutbildningen, tidvis har vi också delat rum. Vi fortsätter väl snart med ett gemensamt projekt?
Alla f d kollegorna i ämnesgrupp omvårdnad: sedan jag bytte jobb har vi inte setts så mycket men vi har en lång historia tillsammans, ända tillbaka till B-kurser och ”överbryggande kurser” – tack för många roliga stunder!
Tack till Birgitte Kolsung (nu i Oslo), Katarina Perälä, Nina Nilsson och Ina Johansson för effektivt och proffsigt administrativt stöd, och en och annan påminnelse.
Tack till alla mina vänner och medarbetare på utvecklingsavdelningen, Lindesbergs lasarett för att ni har stått ut med att jag ibland varit både fysiskt och mentalt frånvarande – det ska bli bättre. Och till alla andra arbetskamrater på plan 5 – tack för stöd och intresse!

Och så till er som ändå är allra viktigast: Tack till dig lilla pappa. Utan din och mammas uppmuntran och tro på att ”allt går bara man vill” hade jag inte suttit här. Tack också till alla er i min stora familj, och naturligtvis speciellt till er – Erik och Astrid! Ni har stöttat och uppmuntrat, men framför allt hela tiden påmint mig om att livet sker här och nu, att det vanliga vardagslivet är det viktigaste.
Och till dig Gunnel, som har gjort samma resa. Vi har puffat på varandra, berömt, tröstat och uppmuntrat – nu är vi framme!

Eva
REFERENCES


Multidisciplinary recording and continuity of care for stroke patients with eating difficulties

Multidisciplinary recording for stroke patients

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Key words: continuity of care, eating difficulties, multidisciplinary care, patient record, stroke

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Multidisciplinary recording and continuity of care for stroke patients with eating difficulties

ABSTRACT

Eating difficulties after stroke are common and can, in addition to being a risk for serious medical complications, impair functional capability, social life and survivor’s self-image. Stroke unit care entails systematic multidisciplinary teamwork and continuity of care. The purpose of this study was to describe (1) multidisciplinary stroke care as represented in patient records for patients with eating difficulties and (2) the written information that was transferred from hospital to elderly care. Data from 59 patient records were analysed with descriptive statistics and by categorisation of phrases. Signs of multidisciplinary collaboration to manage eating problems were scarce in the records. While two notes from physiotherapists were found, nurses contributed with 78% of all notes (n = 358). Screening of swallowing and body weight was documented for most patients, whereas data on nutritional status and eating were largely lacking. The majority of notes represented patients’ handling of food in the mouth, swallowing and lack of energy. Care plans were unstructured and few contained steps for managing eating. Discharge summaries held poor information on care related to eating difficulties. The language of all professionals was mostly unspecific. However, notes from speech-language therapists were comprehensive and entailed information on follow-up and patient participation.

Keywords: continuity of care, eating difficulties, multidisciplinary care, patient record, stroke
INTRODUCTION

Multidisciplinary stroke care

Stroke is one of the major diseases worldwide and national guidelines for stroke care have been developed in most Western countries to ensure quality of care for this large patient group (Sacco, Adams et al., 2005; Socialstyrelsen, 2005). There is ample scientific evidence supporting treatment in stroke units (Cochrane Collaboration, 2001). The stroke unit strategy is based on the multidisciplinary team (usually including physicians, nurses, physiotherapists, occupational therapists (OT), speech-language therapist (SLT) and social worker), coordinated multidisciplinary teamwork and regular programmes for education and training of staff. Multidisciplinary work has been recommended as a successful strategy but little knowledge exists on how collaboration between different professionals in the team contributes to effective stroke care (Langhorne & Pollock, 2002; Baxter & Brumfitt, 2008). In the literature the term multidisciplinary is used along with various terms, including teamwork, multiprofessional, interdisciplinary and interprofessional work. Following the nomenclature in the Swedish national guidelines, the term multidisciplinary is used. Several authors have stressed the importance of interprofessional education and training to accomplish successful multidisciplinary work (D’Amour, Ferrada-Videla, Rodrigues, & Beaulieu, 2006) and accurate discharge decisions (Bowles, Foust, & Naylor, 2003). An area where multidisciplinary collaboration is necessary is the care of patients with severe eating difficulties, as for example in stroke care.
Eating difficulties after stroke

In hospitalised stroke patients eating difficulties appear in 40 – 80% of the patients (Poels, Brinkman-Zijlker, Dijkstra, & Postema, 2007; Westergren, Karlsson, Andersson, Ohlsson, & Hallberg, 2001a). Living with such difficulties has been demonstrated to cause suffering, including fear of choking, shame about one’s appearance, humiliating dependency in eating situations (Jacobsson, Axelsson, Österlind, & Norberg, 2000), practical difficulties in mealtime situations, but also a desire for independence and a normal life (Carlsson, Ehrenberg, & Ehnfors, 2004). Nutritional and eating-related factors have been identified as important aspects of quality of life after stroke (Perry & McLaren, 2004). Obviously, eating difficulties may result in nutritional decline and the consequences of malnutrition, such as slow recovery and poorer functioning in activities of daily living (ADL), significantly longer length of stay in hospital (Kondrup, Johansen et al., 2002) and increased incidence of infections (Chandra, 2002), have been described in a number of studies since the 1970s. Early screening and assessment of eating difficulties are imperative for management of these problems, as well as for the prevention of complications such as malnutrition (Westergren, 2006).

Assessment of eating difficulties

Comprehensive assessment of functions and activities are basic features in stroke unit care (Langhorne & Pollock, 2002). Screening and early management of swallowing problems (dysphagia) is emphasised, as well as assessment of nutritional status and related interventions (FOOD Trial Collaboration, 2003). Two screening instruments for eating difficulties after stroke with similar content exist (McLaren & Dickerson, 2000; Westergren, Ohlsson, & Hallberg,
Westergren and colleagues’ (2001b) instrument entails three categories: ingestion, deglutition and energy. Ingestion refers to sitting position, handling food on the plate and transporting it to the mouth. Deglutition concerns handling of food in the mouth and swallowing while energy includes alertness, eating speed and quantity of consumed food. Several instruments for assessing ADL include eating and drinking activities. The ADL taxonomy (Törnquist & Sonn, 1994), which is commonly used in Swedish occupational therapy, comprises assessment of three sequences of eating-related actions: getting food from a plate into one’s mouth and eating, getting liquid from a glass or cup into one’s mouth and drinking and helping oneself to food and liquid, including cutting the food. In speech-language therapy assessment of functions related to eating and swallowing is a prominent element of professional performance.

**Continuity of care**

A large proportion of persons who have survived a stroke have decreased autonomy that is caused by speech or language impairment, depression and impaired memory (Kumlien, Axelsson, Ljunggren, & Winblad, 1999; Tatemichi, Desmond et al., 1994), stressing the importance of continuity of care and transfer of adequate information among different professionals and care providers. Continuity of care has frequently been addressed and studied from a wide range of perspectives (CEN, 2000; Sparbel & Anderson, 2000). In the case of persons with chronic illness, however, there is lack of consensus about what constitutes continuity of care and lack of criteria for quality in the process (Haggerty, Reid et al., 2003). In the present paper Haggerty and colleagues’ definition of continuity is used: “Continuity is the degree to which a series of discrete healthcare events is experienced as coherent and connected and consistent with the patient’s
medical needs and personal context (Haggerty, Reid et al., 2003, p. 1221). Lately, continuity has been identified as an important aspect of patient safety (Boockvar & Burack, 2007). Intra- and inter-organisational continuity of care requires adequate communication on personal and system levels and can be obstructed by role confusion, rivalry between professional groups and use of professional language (Atwal & Caldwell, 2002; Pethybridge, 2004). One important tool for securing quality and continuity of care is the patient record.

**The patient record**

Informational continuity is the use of information on prior care and personal circumstances to provide appropriate, subsequent care for each individual (Haggerty, Reid et al., 2003). One important tool for providing informational continuity is the patient record. According to Swedish law, all registered health care professionals are obliged to document relevant information on the patient’s conditions, planned and performed interventions and information given in the patient record (SFS 2008:355). A written care plan serves as a communication tool facilitating coordination of care between professionals and care sites involved in the patient’s care. Swedish national guidelines for stroke care emphasise continuity of care and multidisciplinary documentation in the patient record that is easy to access, unambiguous and efficient (Socialstyrelsen, 2005). A discharge summary should reach elderly care staff in appropriate time before patient transfer (Bull & Roberts, 2001) and contain essential information about previous care, planned interventions and present status, including the patient’s communication ability and functional capacity (Ehrenberg, Ehnfors, & Thorell-Ekstrand, 1996; SOSFS 2005:27). Although informational continuity for persons with chronic illness (e.g., stroke) calls for structured and adequate documentation, few researchers have studied this aspect of continuous stroke care.
Information on eating problems has been reported to be scarce among stroke patients discharged to nursing homes (Kumlien, et al., 1999). Two Swedish projects investigated documentation in stroke care units and information transfer at discharge (Hassler & Krakau, 2005; Olofsson, Wittlöw, Waldermarsson, Sederholm, & Jacobsson, 2002). Both projects reported that the patient record was a poorly structured and insufficient source of information, that vital information often was missing and that information was often duplicated. Olofsson and colleagues (2002) concluded that judgements and summaries necessary for subsequent care were frequently missing and that the information deficiencies might be a threat to patient safety. More standardised documentation, preferably electronic health records, and checklists for information transfer were suggested. One such checklist has been tested in discharge planning for stroke patients, revealing risk related to swallowing for one third of the patients (Åberg & Almborg, 2005).

To conclude, persons with stroke and eating difficulties constitute a large and vulnerable group of patients in need of comprehensive and continuous care. Extensive knowledge about the manifestations and consequences of eating difficulties exists and instruments for assessing eating function are available. According to Swedish legislation, the county council is responsible for acute health care, such as stroke unit care, and the municipality is responsible for elderly care (social services, nursing care, residential homes and rehabilitation for persons ≥ 65 years). In such multifaceted and prolonged care, care planning and informational continuity are cornerstones. However, knowledge is needed about multidisciplinary informational continuity and no study was found that had evaluated record content for stroke patients with eating difficulties.
The aims were to describe (1) multidisciplinary stroke care as represented in patient records for patients with eating difficulties, and (2) the record content transferred from hospital to elderly care at discharge.

MATERIAL AND METHODS

Setting

This retrospective survey took place at a Swedish local hospital from January to July 2003. The policy of the hospital was that patients with a stroke diagnosis should be cared for in the stroke unit. The stroke unit included combined acute and rehabilitation care (SUTC, 1997) with a care policy and multidisciplinary staffing based on the Swedish national guidelines (Socialstyrelsen, 2000). Care planning conferences were held once a week with all professionals participating. For most patients discharged to elderly care, discharge planning meetings, which included team members, patients and their next-of-kin and representatives from the elderly care organisation, were held at the stroke unit. All staff at the stroke unit received regular and joint training according to the Swedish national guidelines.

Sample

Records representing the care for patients with a stroke diagnosis (n=106) who were discharged during the actual period were consecutively included. Of these 106 records, 59 contained one or more notes on eating difficulties and were selected for the sample. Patient characteristics are reported in Table I. The records were paper-based and consisted of several documents: (1) a
typewritten record with documentation from physicians, physiotherapists and OTs, (2) a handwritten nursing documentation, (3) a medication chart, (4) a stroke monitoring form, (5) letters of referral and (6) a discharge summary. Additional to the physicians’ typewritten letters of referral to primary health care, two standardised formats with pre-formulated keywords were used for the handwritten discharge summary. One document primarily contained information about medical treatment from the physician, whereas the other held information on nursing care and rehabilitation, with ADL function categorised according to the Katz ADL index (Katz, & Akbom, 1976). The category “Food intake” had three pre-formulated response alternatives: totally dependent, partly dependent and independent, for which pre-formulated information “Needs reminder”, “Needs supervision” or “Active assistance” could be marked.

Table I. Characteristics of patients with eating difficulties discharged from hospital after stroke (n=59)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Men (n= 27)</th>
<th>Women (n= 32)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Md (q1-q3)</td>
<td>78 (71-84)</td>
<td>82 (79-85)</td>
</tr>
<tr>
<td>Length of stay, days</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Md (q1-q3)</td>
<td>27 (11-45)</td>
<td>28.5 (11-42)</td>
</tr>
<tr>
<td>Discharge destination [n (%)]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home</td>
<td>12 (44)</td>
<td>12 (37)</td>
</tr>
<tr>
<td>Residential home care</td>
<td>15 (56)</td>
<td>20 (63)</td>
</tr>
</tbody>
</table>

The audit protocol

Few instruments have been validated for audit of record comprehensiveness ( Ehrenberg et al., 2001) and no instrument was found that suited the purpose of this study. Thus, a protocol was designed based on two existing instruments for record audit (Ehnfors & Smedby, 1993; Thorell-Ekstrand & Björvell, 1995) and on two tools for assessing eating ability after stroke (McLaren &
The protocol contained 30 items covering demographic data (5 items), data about eating difficulties and related problems (16 items) and on care planning (9 items). The definition of care plan in this study was: a written plan for the care of the patient based on descriptions of the actual care needs and including interventions to restore or improve functional health. There was a mix of response alternatives, including yes/no, several alternatives or open answers. Nine items offered the possibility to insert text from the patient record. Based on content and comprehensiveness in relation to what was recorded in the patient record, the quality of the care plan was rated on a 3-point scale with 1 denoting poor quality, 2 moderate quality and 3 adequate quality. The comprehensiveness of the discharge summary on patients’ condition, interventions and prevention related to eating difficulties, and patient’s communicative ability, was rated on another 3-point scale. The protocol was pilot-tested with the consequence that five items required revision.

**Procedure**

Information from the six parts of the patient record described above was extracted. The first author collected all the data; no photocopies were made of the records and all personal identification was removed. Permission to conduct the study was obtained by the director of the Department of Internal Medicine, and the project was approved by The Research Ethics Committee, Örebro County Council, Sweden (Dnr 434/03). Inter-rater agreement on the items in the final protocol was tested by having a second reviewer auditing 10% (6 records) of the sample. Inter-rater agreement for all items ranged from total (100%) agreement on 17 items, 80-90% for 8 items, 70% on three and 60% on two items. The κ-coefficient value for a random sample of 11 items ranged from moderate (κ= 0.41-0.60) for three items to very good (κ= 0.81-1.0) for eight
items (Altman, 1991), which was considered sufficient.

Data analysis

The selected documents were scrutinised seeking data related to the items in the audit protocol. The audit of discharge summaries intended to capture completeness in the information that was transferred to elderly care in relation to what had been recorded about eating difficulties during the completed episode of care. All text concerning eating difficulties and nutrition was extracted from the records and categorised according to the items in the protocol. Because many notes were unspecific, the categorisation entailed elements of interpretation related to the stroke care context. Data related to eating that did not fit into the protocol items were categorised “Other eating problems”. During data analysis, that category was further intuitively divided into six categories. Demographic data and frequencies of recordings were analysed using descriptive statistics.

RESULTS

Eating difficulties recorded in the patient record

The records (n= 59) were all in paper format and had both hand- and typewritten notes varying in extent depending on length of stay and complexity of care. In total, 358 notes on eating difficulties were found (Table II). Forty-five (76%) of the patient records entailing notes on eating difficulties included a care plan but only one explicit care plan for eating difficulties was found. Fifty-two (88%) records held notes on screening for dysphagia at admission. No
comprehensive assessment of nutritional status or eating ability was found and only one single nutrition chart appeared. Five records (9%) held recordings of tube feeding. Notes on the use and evaluation of assistive devices for eating occurred in two patient records. As shown in Table II, problem statements related to eating were mainly found in the nursing documentation. The most frequently represented category of eating difficulties was “Handling of food in the mouth and swallowing” (105 notes, 29%) while other frequently occurring aspects of eating were “Fatigue/Lack of energy” (59 notes, 17%) and “Appetite/Eats poorly” (54 notes, 15%). “Other eating problems” held six categories: “Assisted eating”, “Modified consistency diet”, “Denture/Oral problems”, “Spatial neglect/Visual field loss”, “Rejects food” and “Nutritional problems/Enteral or parenteral feeding”. None of those notes showed a detailed description of the actual problems. A large share of notes was unspecific and therefore difficult to clarify whether these notes referred to appetite, functional eating or psychological aspects/depression (e.g., “Mr X eats poorly, needs help”). Terminology was not consistent and varied between and within professionals. SLT was the only profession that used the term dysphagia; physicians and nurses used pharyngeal paralysis or swallowing problems. Only the OTs used a language that showed some standardisation, using the ADL taxonomy (Törnquist & Sonn, 1994). An example follows of a problem statement summarising an occupational therapy assessment: “Manages food intake independently”. Frequencies of statements on eating difficulties by profession are presented in Table II.
Table II. Frequencies of statements (n=358) on eating difficulties and recording professions in patient records (n=59).

<table>
<thead>
<tr>
<th>Recording profession</th>
<th>Physician</th>
<th>Registered nurse</th>
<th>Occupational therapist</th>
<th>Physio-Therapist</th>
<th>Speech-language therapist</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of problem statements*, n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Ingestion</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Handling food on the plate</td>
<td>0 (0)</td>
<td>4 (67)</td>
<td>2 (33)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>6 (2)</td>
</tr>
<tr>
<td>2. Transporting food to the mouth</td>
<td>2 (50)</td>
<td>2 (50)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>4 (1)</td>
</tr>
<tr>
<td><strong>Deglutition</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Close lips and bite</td>
<td>5 (50)</td>
<td>3 (30)</td>
<td>1 (10)</td>
<td>0 (0)</td>
<td>1 (10)</td>
<td>10 (3)</td>
</tr>
<tr>
<td>4. Handling food in the mouth and swallowing</td>
<td>29 (27)</td>
<td>62 (59)</td>
<td>1 (1)</td>
<td>2 (2)</td>
<td>11 (10)</td>
<td>105 (29)</td>
</tr>
<tr>
<td><strong>Energy</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Fatigue/Energy</td>
<td>3 (5)</td>
<td>55 (93)</td>
<td>1 (2)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>59 (17)</td>
</tr>
<tr>
<td>6. Aberrant eating speed</td>
<td>0 (0)</td>
<td>2 (100)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>2 (1)</td>
</tr>
<tr>
<td>7. Appetite/&quot;Eats poorly&quot;*</td>
<td>3 (6)</td>
<td>51 (94)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>54 (15)</td>
</tr>
<tr>
<td><strong>Nausea</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Nausea/Vomiting Regurgitation</td>
<td>2 (4)</td>
<td>46 (6)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>48 (13)</td>
</tr>
<tr>
<td><strong>Other eating related problems</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Assisted eating</td>
<td>0 (0)</td>
<td>17 (63)</td>
<td>10 (37)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>27 (8)</td>
</tr>
<tr>
<td>10. Modified consistence</td>
<td>0 (0)</td>
<td>6 (100.0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>6 (2)</td>
</tr>
<tr>
<td>11. Denture/Oral problems</td>
<td>1 (14)</td>
<td>6 (86)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>7 (2)</td>
</tr>
<tr>
<td>12. Neglect/Visual loss</td>
<td>0 (0)</td>
<td>3 (75)</td>
<td>1 (25)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>4 (1)</td>
</tr>
<tr>
<td>13. Rejects food</td>
<td>1 (8)</td>
<td>11 (92)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>12 (3)</td>
</tr>
<tr>
<td>14. Nutritional problems, enteral and parenteral feeding</td>
<td>1 (7)</td>
<td>12 (86)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (7)</td>
<td>14 (4)</td>
</tr>
<tr>
<td>Total number of notes per profession</td>
<td>47 (13)</td>
<td>280 (78)</td>
<td>16 (4)</td>
<td>2 (1)</td>
<td>13 (4)</td>
<td>358 (100)</td>
</tr>
</tbody>
</table>

* Statements comprising one sentence or more.
The number of eating difficulties and nutritional problems described for a patient varied from one to five. Five records had one eating difficulty stated once while eighteen records contained two eating difficulties, 16 records had three, 10 records included four and 3 records comprised five problems. The majority of records (n=52, 88%), however, had only notes on the patients’ current problems, often lacking professional description and with few signs of planned or performed interventions, goals and outcomes. In more than 50% of the records, and in some of them repeatedly, there was only a note stating a change in the patients’ situation (an implicit outcome), presuming both a problem and interventions that were not previously described (e.g., “Mr X managed to eat without assistance today”). Duplicated information among professions appeared in 11 records (19%). In the nursing notes, however, the same problem was repeated several times without any subsequent care plan in 12 records (20%). Those records contained, for example, multiple notes stating that the patient “eats poorly” with no, or an unspecific description of the problem or interventions to manage the problem. Nursing notes were sometimes contradictory; with one nurse stating a problem (i.e. that the patient had swallowing difficulties) and another nurse within a short time later recording that there was no problem. Patient participation and preferences were recorded in relation to eating difficulties in two (3%) patient records.

**Multidisciplinary recording**

The typewritten part of the patient record was systematically structured with keywords, whereas the handwritten nursing documentation was more unstructured though some keywords were used. No common keywords were used by all professions. Multidisciplinary care planning conferences were carefully documented. Most records contained coherent but unstructured multidisciplinary
care plans for many physical functions, except for eating. “Handling food in the mouth and swallowing” was the category that had most notes and the most multidisciplinary representation, with 62 notes from nurses, 29 notes from physicians, 11 from SLTs, 2 from physiotherapists and 1 from an OT (Table II). Twenty-eight (27%) of those notes described interventions and 22 (21%) were judged as outcomes, though not always written as such. The only profession recording interventions related to risks (e.g., aspiration) was the SLT, who prescribed risk management (8 notes, 2%). Patient participation or education related to eating difficulties was only recorded by SLTs (8 notes, 2%). Out of three patients who each had five eating difficulties recorded, no one had notes on multidisciplinary care for their extensive and complex eating problems. The documentation in the patient record of one of these patients is summarised below.

A man 78 years old (Mr A) was discharged home after 63 days in hospital. During hospital stay, problems associated with fatigue, nausea/vomiting, lack of appetite, need for assisted eating and deteriorated nutritional status were recorded by nurses (28 notes) and physicians (2 notes). A care plan for nutritional problems was found with interventions only described in four notes while goals were entirely missing. Some degree of evaluation related to the care plan was present in three notes. Twenty notes by nurses were unspecific statements: “Has eaten poorly today”, but also notes such as “Mr A has been eating independently in the dining room. He is more alert and feeling much better” occurred. In the record it was impossible to identify the contributing interventions from the various professionals for this progress. At discharge, the eating difficulties appeared to have declined. No discharge summary was found.
Discharge summaries and informational continuity

All patients but three (n=56, 95%) had been cared for in the stroke unit. Forty-seven records contained discharge summaries, including some kind of care plan (80 %), whereof 36 (77%) held information on the patients’ eating ability. Generally, discharge summaries were lacking comprehensiveness and care plans showed unsatisfactory quality in 21 (45%) records, moderate in 24 (51%) and adequate in 2 (4%). Individual goals and need for nutritional support or assistive devices related to eating were absent. Information comprehensiveness in discharge summaries on the patients’ condition, interventions and prevention related to eating difficulties and patients’ communicative ability are shown in Table III. A short description of a discharge summary is given below.

A 78-year-old woman with diabetes (Mrs. B) was discharged to residential home care after 49 days at the stroke unit. A few notes by nurses about the need for assisted eating and modified consistency diet appeared in the record. Notes about problems with posture when sitting and severe problems related to visual field loss were made by nurses, OTs and physiotherapists but without reference to eating. The discharge summary included very brief information on visual field loss, improved posture, communication ability and a statement that Mrs B was “independent in mealtime activities”. The summary contained no information about the provided interventions with modified consistency diet and assisted eating, no information about problems related to visual field loss and nothing about individual goals. However, there was a referral for follow-up by an occupational therapist.
Table III. Comprehensiveness of information on eating difficulties in discharge summaries (n= 47) as displayed by frequency and percent.

| Information present in discharge summaries about important components of patient’s care: | Information comprehensiveness |
|---|---|---|---|
| | No information (score 1) n (%) | Partial information (score 2) n (%) | Comprehensive information (score 3) n (%) |
| Care history and interventions related to eating difficulties | 44 (94) | 2 (4) | 1 (2) |
| Actual eating difficulties at discharge | 18 (38) | 27 (57) | 2 (4) |
| Prevention related to eating difficulties | 45 (96) | 1 (2) | 1 (2) |
| Communicative ability | 23 (49) | 12 (25) | 12 (25) |

**DISCUSSION**

All except three patients had been cared for at a stroke unit where multidisciplinary teamwork is a cornerstone and where guidelines for evidence-based stroke care were implemented. The analysis and interpretation of the data from the patient record, however, showed few traces of multidisciplinary work or evidence-based care concerning patients’ eating difficulties.

**Identifying and verbalising eating difficulties**

In occupational and physiotherapy systematic assessment of functions and activities is a basic component of professional performance, represented to some degree in the records in this study. Further, physicians’ judgements and diagnoses were systematically recorded. Nurses’ recording,
on the other hand, showed few signs of systematic assessment. Lack of routines, lack of knowledge (Kondrup et al, 2002) and lack of time (Kim & Park, 2005) have been suggested reasons for the scarcity of assessments of eating and nutrition, ultimately affecting patients’ continuity of care (Sparbel & Anderson, 2000). In a British, national audit of stroke care, however, nurses were found to document both assessment of swallowing and nutritional status to a great extent (Lennon, Clarke, et al., 2007). In the present study almost all patients were cared for in a stroke unit where staff had regular education in identifying and managing stroke-related problems, such as eating difficulties. Consequently, knowledge about prevalent patient problems and risks could be expected to be high among all professionals. Reasons for poor quality of information in the patient record is suggested to be ward-specific “custom and practice” as to what to record and how to use the patient record, including information routinely being communicated verbally (Perry, 1997; Lingard, Conn et al., 2007). The surprising absence of notes on such an important and commonly used aid as assistive devices related to eating might be caused by such a tradition.

In the Swedish language the expression for “being a poor eater” (ätte dåligt) is an unspecific expression that can represent bad appetite or low food consumption, but also physical (having problems performing a meal independently), psychological or social problems (not wanting to eat or eating poor or unhealthy food), causing difficulty to interpret this frequently used expression, both in everyday care and in record audits. Several expressions were found stating an unspecific eating problem. Similar experiences with unspecific statements were reported by Perry (1997) in a study of nutrition-related recordings in care plans for patients with various health problems and by Hellesø (2006) studying information in discharge notes. The recorded statements on eating difficulties, as displayed per profession in Table II, mirror the fact that health care professionals
have different focus when caring for patients with eating difficulties. For instance, physicians’
notes were largely restricted to a few categories, whereas nurses’ notes were spread over all 14
categories, with particular emphasis on “Handling food in the mouth and swallowing”,
“Fatigue/Energy”, Appetite/Eats poorly” and “Nausea/Vomiting/Regurgitation”. OTs made most
notes in the category “Assisted eating”, showing a focus on activity with independence as a goal.

Multidisciplinary collaboration and informational continuity

Successful multidisciplinary work has been suggested to presuppose a mutual value base (Atwal
& Caldwell, 2002; Long, Kneafsey, Ryan & Berry, 2002); a common ground that is not self-
evident and may be complicated by professional differences related to different professional
knowledge and skills, role and identity and power and status (Baxter & Brumfitt, 2008). This
study showed team members recording in their profession-specific parts of the patient record.
Multidisciplinary collaboration did not seem to be a salient feature, except in notes from care
planning conferences. Signs of collaboration related to eating difficulties were, however, scarce
in those notes and only one care plan on eating difficulties was found. Without a specific plan,
the care given may be directionless and thus lack coordination and continuity. The majority of
notes related to eating were made by nurses. Eating, assistive devices and meal preparation as
aspects of ADL were surprisingly absent in recordings made by OTs, as were nutritional aspects
in the recordings of physicians. This finding indicates an absence of interprofessional
collaboration as well as lack of mutual knowledge and value base in the team. In a stroke unit
context, however, a mutual multidisciplinary understanding of problems associated with eating
can be expected. Statements such as “Patient eats better” could be understood by the team as
implying that the patient is recovering from dysphagia, but is still in need of modified
consistency diet and assisted eating or assistive devices. In that case the note can be interpreted as a rough evaluation of an implicit care plan even though it was impossible to recognise what interventions caused that progress. Similar experiences were made by Hellesø (2006) who found unspecific notes on patients’ appetite. The author suggested that nurses assumed that colleagues would know what these statements implied. Perry (1997) found that nurses considered themselves as having the major responsibility for nutritional assessment. According to the amount of notes made by nurses in this study (Table II), the same situation could be anticipated in this stroke unit. Little information on patient participation was found in the records. This observation is in accordance with a study on rehabilitation after stroke (Bendz, 2003), where it was found that neither patients nor health care professionals expressed distinct goals for the rehabilitation.

Informational continuity includes the completeness and availability of information transferred between health care providers and the extent to which existing information is acknowledged and used (Haggerty et al., 2003). The problems of informational continuity when discharging patients from hospital have been well documented and include, among other things, poor communication, inadequate notice of discharge and inattention to patient needs. These problems of informational continuity make it difficult for staff in elderly care to plan for continuing care (Boockvar & Burack, 2007; McKenna, Keeney, Glenn, & Gordon, 2000). In our study only discharge summaries were studied, not discharge planning conferences or verbal information exchange. Therefore, no conclusion can be drawn on the total quality of the discharge information. However, the discharge summary is a written document that remains unchanged and constitutes proof of information from the previous care provider. Being of such importance, it is surprising that so many of the audited discharge summaries had poor quality and lacked vital information.
for continuous care, such as information on patients’ weight loss, assistive devices and need for nutritional support. The need for standardised templates for information transfer has been advocated for improving information quality (Olofsson et al., 2000; Hellesø, 2006). The forms for the discharge summaries in this study were developed in the 1990s, were not structured according to the care process, and had limited space for individual notes. Nurses seemed to be responsible for most of the recordings. In this study with stroke unit professionals being experts, discharge summaries could be expected to contain comprehensive information on how to care for these patients, but no summary was found containing all the information needed to plan continuing care related to eating difficulties. With a more structured format, including nutritional needs, the discharge summary might have been more comprehensive and patient-centred.

STUDY LIMITATIONS

As described earlier, there are several reasons why records may not give an accurate reflection of the care provided. In Swedish nursing and occupational therapy there is a strong tradition of transferring information verbally at discharge to colleagues in elderly care. That information can obviously not be captured by auditing the record. The accuracy of recorded data has not been studied extensively, which may result in uncertainty on data validity. Two complementary perspectives have been proposed to capture accuracy in record audits: ‘correctness’ (the proportion of documentation that is in agreement with the actual circumstances) and ‘completeness’ (the proportion of observations and planning that are documented) (Ehrenberg & Ehnfors, 2001). In the present study only completeness was studied. The first author who collected the data had considerable experience as a geriatric nurse. This experience might have
resulted in positive interpretations of vague statements in the records that a researcher with another background would not have made. Therefore, to deal with this risk of bias the data and the manuscript have been processed by all authors and discussed at multi-professional research seminars. To further mitigate the limitations of the record audit, a sample of observations of patients’ eating ability and interventions performed by health care professionals would have been fruitful and such a multi-method study was performed after the study presented here.

CONCLUSION

The findings present a picture of stroke care in which eating difficulties were documented in more than 50% of the patients’ records but with few signs of systematic assessment and documentation, as well as with few traces of multidisciplinary collaboration in the field of eating. Patient participation was only visible in a few records and informational continuity, i.e. the availability and use of information on prior care and circumstances to provide relevant, subsequent care as represented in the discharge summaries, showed poor quality. To provide safe and high quality care for stroke patients with eating difficulties, stroke pathways need to hold standards for assessment of eating ability, profession specific interventions and multidisciplinary collaboration to cover all the aspects of care for these vulnerable patients. Two important issues for further research are to investigate whether professional perspectives on eating difficulties after stroke differ, and if so, how different perspectives influence multidisciplinary collaboration. Other questions that need investigation are what information – written and verbal - concerning stroke patients’ care needs is transferred to elderly care at discharge and what is the caregivers’ need for information.

ACKNOWLEDGEMENTS
This study was supported by the Örebro County Council and by Nutritionsnätet (Swedish nursing network for nutrition).

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Informational continuity at discharge in patients with eating difficulties after stroke

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Key words: continuity of care, discharge, eating difficulties, information transfer, nursing, record audit, stroke

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Informational continuity at discharge in patients with eating difficulties after stroke

ABSTRACT

BACKGROUND

Eating difficulties are frequent and serious problems in stroke patients. Screening of eating difficulties can predict undernutrition and subsequent care needs. For continuous care, information transferred to the next care setting has to be comprehensive and accurate.

AIM

To describe the accuracy in information transfer on eating difficulties in stroke patients discharged to municipal care, and how nursing staff in municipal care perceived the accuracy of eating-related information that was transferred from the hospital.

METHODS

A sample of 15 triads was investigated, each including one stroke patient, his patient record and discharge summary, as well as two nursing staff in municipal care to which he was discharged. Data were collected by observation of patients’ eating, record audit and interviews with nurses. Data were analysed using content analysis.

RESULTS

Coherence in documentation of eating difficulties and accuracy of transferred information were poor based on record audits and as perceived by the municipal nurses. Although all patients were at risk for undernutrition and had multiple eating difficulties, explicit care plans were lacking.

RELEVANCE TO CLINICAL PRACTICE

For safe and continuous stroke care, nurses in hospitals and municipal care need to learn and practice systematic identification of eating difficulties and standardised terminology.
INTRODUCTION

Eating difficulties after stroke

During the acute phase of stroke and during the first half year after the stroke, eating difficulties are frequent and may even be life-threatening (Perry & McLaren, 2003; Poels et al, 2006). In a Swedish national follow-up two years after stroke, 7% of persons with stroke reported a need for assisted eating (Socialstyrelsen, 2004). Several aspects of eating difficulties have been identified, including problems with handling food on the plate, swallowing and lack of energy to complete a meal. Systematic screening for those components can predict undernutrition, need for assisted eating, length of hospital stay and level of care after discharge (Westergren et al 2002; in press). National guidelines for stroke care, mandate screening for and early management of swallowing impairment, as well as assessment of nutritional risk and interventions to prevent nutritional decline and related serious consequences (e.g., aspiration pneumonia and reduced energy for rehabilitation) (Socialstyrelsen, 2005). Screening of not only swallowing but also all the components of the eating process has been proposed to identify these problems (Westergren, 2006). In a Scandinavian survey registered nurses (RNs) and physicians, who were working in specialities where nutritional problems were common, reported insufficient knowledge in nutritional care (Mowe et al, 2008). Furthermore, in a study on municipal care it was found that managers, kitchen personnel and nursing staff were not educated in nutritional care (Mattsson-Sydner & Fjällström, 2005). In municipal care RNs were found to lack specific
knowledge on how to plan for patients with eating difficulties after stroke (Kumlien, 2005), but successful quality improvement of nutritional care using recurrent assessments combined with individualised care plans has also been reported (Kuosma et al, 2008).

**Continuous stroke care**

Approximately 30,000 persons each year are affected by stroke in Sweden; of these 30,000 persons, 80% are over 65 years of age. Similar to other Western countries, stroke in Sweden is the diagnosis causing the largest volume of days in hospital at an estimated cost of more than 1.1 billion USD per year (Norrving, 2007). At discharge from hospital, 85% of Swedish stroke patients return to their homes, with or without support from home care while the remaining 15% need comprehensive care in the municipality (Socialstyrelsen, 2007). To ensure safe and continuous care for this large group of older patients information transferred to the next care provider has to be comprehensive and accurate, which is also mandated in Swedish regulations (SOSF 2005:27).

Although continuity of care has been studied and discussed from a range of perspectives, there is still a lack of definition and consensus about what constitutes the phenomenon and criteria for quality in the process (Haggerty et al, 2003). In this paper two aspects of continuity of care as defined by Haggerty and co-workers will be used:

- **Informational continuity** – the use of information on past events and personal circumstances to make current care appropriate for each individual.

- **Management continuity** – a consistent and coherent approach to the management of a health condition that is responsive to a patient’s changing needs (Haggerty et al, 2003, p. 1220).

An important tool for the provision of informational continuity is the patient record (PR). Swedish registered health care professionals are mandated to document in the PR relevant
information on the individual’s condition, including planned and performed interventions and
information provided to the patient (SFS 2008:355). Accordingly, it is reasonable to expect
PRs to provide essential information on the state of the patient, related care and plans for
further care. However, studies on representation of care in PRs have revealed serious
deficiencies in such as quality, comprehensiveness and accuracy (Gunningberg & Ehrenberg,
2004; Kim & Park, 2005). Management continuity is manifested in co-ordinated care
planning and discharge summaries. The discharge summary is an important document for
continuity of care and should contain essential information about a patient’s previous care,
planned interventions and present health status, including communicative and functional
capacity (Ehrenberg et al, 1996).

Swedish law mandates not only comprehensive information transfer but also co-ordinated
care planning (including the patient and next of kin, representatives from the hospital, social
services and health care in the municipality) when a person needing such services is
discharged from hospital (SOSFS 2005:27). Adequate discharge planning is a crucial and
complex component of continuity of care and one way of handling co-ordinated care planning
(Hellesö et al, 2005). Despite that discharge planning is an everyday activity for RNs, studies
have reported low quality in discharge planning for older patients (Johnson et al, 2003;
Hellesö et al, 2004). Despite its obvious importance, specific knowledge about the content of
information transfer at discharge of stroke patients to municipal care is scarce. In one of the
few studies that was found, information on stroke patients’ eating difficulties was seldom
recorded in the discharge summaries (Kumlien et al, 1999). A Swedish report found that the
PR was poorly structured and an insufficient source of information and that vital information
was often missing, implying a potential threat to patient safety. More standardised
documentation and checklists for information transfer were suggested (Olofsson et al, 2002).
One such web-based checklist for assessment of functions, activity and risk for complications has been tested in discharge planning for stroke patients, revealing risk related to swallowing in one third of the patients (Åberg & Almborg, 2005). In recent years web-based softwares have been introduced in large parts of Sweden for handling discharge planning and information transfer.

To conclude, researchers have pointed out several obstacles for the provision of high quality and continuity of care in stroke patients with eating difficulties discharged from hospital. Health care professionals have been found to lack knowledge on eating difficulties, resulting in a deficiency of appropriate routines for identification and management of patients’ eating, feeding and nutritional difficulties. Ineffective discharge planning has also been noted and information transfer from hospital to municipal care has been described as a complex and insecure process. However, no study has focused on the process of informational continuity for stroke patients with eating difficulties. Also, knowledge is scarce on how nursing staff in municipal care perceive the accuracy of transferred information.

AIMS

The aim of this study was to describe the accuracy in information transfer on eating difficulties in stroke patients discharged from hospital to municipal care. More specifically, to determine if:

- there was accuracy and comprehensiveness in the documentation of patients’ eating difficulties compared with patient status, and
- RNs and assistant nurses (ANs) in municipal care perceived that eating-related information transferred from the hospital was accurate.
METHODS

Design

A prospective, descriptive design was used with data from three sources: patient records and discharge summaries, systematic observations of patients and interviews with nursing staff.

Setting

The settings were a stroke unit in a Swedish local hospital and three adjacent municipalities. Six municipal care units were involved (residential homes and rehabilitation units) and one home health care team. Planning for continuity of care was done in two ways: (1) for some patients, a discharge planning conference was held at hospital and (2) for other patients, care planning took place when they arrived at the municipal care facility. A web-based tool for information transfer and co-ordinated care planning (here called ITT) was used for all patients to achieve information exchange among hospitals, primary health care and municipal care. This tool was not integrated into the PR, which was paper-based. Further, telephone “hand-over” to the receiving colleague in municipal care was made by registered nurses for 11 of the 15 patients. Only written discharge information was included in this study.

Sample

A convenience sample of 16 triads was selected. One patient chose not to participate, resulting in a final sample of 15 triads. A triad consisted of one patient with stroke, his PR and information in ITT and the nursing staff from the receiving municipal care unit (one RN and one AN). The following inclusion criteria were used: the patients should still have some eating difficulties at discharge; they should be discharged to care in one of the three municipalities; and they should be able to give informed consent, independently or with help
from the next of kin. Inclusion criteria for the nurses were that they should be involved in the care of the actual patient and that they had not been interviewed before in the actual study.

Patients
The patients, six women and nine men, had a mean age of 83 years (SD 6.9) and suffered from multiple problems that were caused by stroke and other disorders. Thirteen patients had one or more additional cardiovascular diagnoses: one patient had diabetes and one rheumatoid arthritis. Fourteen of the 15 patients had been in the stroke unit for more than two weeks and all were identified by the principal author (EC) as being at risk for undernutrition. Four patients were discharged to rehabilitation units and one patient could return home with support from home health care.

Patient records
Both the PR and the discharge summary from the physician to the receiving general practitioner were paper-based, whereas discharge summaries from RNs, occupational therapists and physiotherapists were included in the ITT.

Nurses
Of the 15 RNs participating in the study, 13 were women (all ANs were women). Ten of the RNs were responsible for ≥ 25 patients on an ordinary spell of duty. All ANs worked in smaller patient groups with less than 15 patients. Both RNs and ANs had been in their professions for a long time (i.e. 10 RNs and 7 ANs ≥ 15 years and 3 RNs and 1 AN < 5 years). Three RNs and five ANs had some education in nutrition after their basic education.

Data collection
MEOF-I

To describe the participants’ eating the Minimal Eating Observation Form (MEOF-I) was used. MEOF-I, which contains 11 dichotomized items organised into three categories (ingestion, deglutition and energy), was developed to detect eating difficulties (Westergren et al, 2002; in press). In this study 9 of the 11 items were used:

- ingestion - sitting position, manipulation of food on the plate, transport of food to the mouth
- deglutition - open/close the mouth, manipulation of food in the mouth, swallowing
- energy - eats less than ¾ of normal portion, energy to complete a meal, time to complete a meal

The instrument has been shown to predict undernutrition, need for assisted eating, length of hospital stay and level of care after hospital discharge (Westergren et al, 2002; in press). In a recent study with older patients in hospital and residential home care the instrument’s reliability and validity was found to be good (Westergren et al in press).

MNA-SF

Mini Nutritional Assessment – Short Form (MNA-SF) is a six-question screening tool to identify patients at risk for undernutrition. The six items describe food intake, weight loss, mobility, neuropsychological problems, psychological stress and body mass index (BMI). A score ≤ 12 indicates risk for undernutrition (maximum score is 14). The MNA-SF has been extensively tested for reliability and validity with good results (Rubinstein et al, 2001).

Record audit

A protocol had been developed in an earlier study regarding audit of documentation of eating difficulties in PRs based on the aspects of eating described by Westergren et al (2002) in the
MEOF-I instrument. The instrument was further elaborated with an item for “other eating-related problems” and a structure showing what data occurred in the PR and ITT was established to be used as a coding scheme in this study.

**Interviews**

A structured protocol consisting of 24 questions was designed for the telephone interviews. Of the 24 questions, 23 were multiple-choice (nominal and ordinal level) with a possibility to add the respondent’s comments. The questions covered demographic data (3 items), organisation and responsibilities (7 items), information transfer process (5 items), perceived quality of transferred information (3 items), management of insufficient information from hospital (1 item) and knowledge of eating and nutrition (4 items). The RNs and ANs were asked to appraise the information transferred from hospital in the categories ‘sufficient’, ‘fair but some information missing’, ‘insufficient’, ‘no information’ and ‘wrong information’. One question was open-ended: “Would you please describe this patient’s eating?” The interview protocol was pilot tested in interviews with two RNs, but the pilot results suggested no changes in the questionnaire were required.

**Procedure**

RNs in the stroke unit identified patients with eating difficulties for inclusion in the study. When the discharge decision was made, the principal author met with the patient, and if the patient had communication problems, also with the patient’s next of kin and asked for informed consent. Data were collected from December 2007 to September 2008 on three occasions during the transfer process of each patient. First, in the stroke unit before discharge risk for undernutrition was identified by record audit using the MNA-SF. In addition, patients’ eating ability was observed using MEOF-I. Second, audit of PRs for the care episode,
including ITT, was performed after discharge. All text in the PR and ITT that included information on the patients’ eating and nutrition was transcribed to a Word file for subsequent analysis. Additionally, demographic data, medical diagnosis, length of hospital stay and discharge destination were extracted. Third, interviews with RNs and ANs in municipal care were performed two weeks after discharge and thus it could be assumed that they had sufficient time to assess patients’ eating difficulties. One week after discharge of each participating patient, the manager of each receiving municipal care unit was contacted. Via the managers, nursing staff caring for the patients were identified, contacted by telephone and asked for consent. All invited RNs and ANs accepted to participate in the interview. The RNs and the ANs’ answers were written by hand in the protocol during the telephone interview. Each interview lasted from 20 to 40 minutes.

**Ethical considerations**

Planning research on older people with severe impairments, often aggravated by communication problems, is a delicate matter requiring some awareness of the problems that can occur and openness for changing data collection practices if participants express discomfort. Because the way people eat after stroke may involve feelings of shame and embarrassment (Jacobsson et al, 2000), observation of a meal for research purposes has to be handled with tact and subtlety. Therefore, when asking for informed consent, the participants were told that participation was voluntary and that they could withdraw from the study without explanation and without adverse consequences. The researcher had first planned to sit close to the observed patients, but based on the pilot test decided to conduct the observation more discretely from a distance of five metres.
Directors and managers of care in the three municipalities and hospital stroke unit gave their permission for the collection of the data. Patients and RNs in the stroke unit and nursing staff in the three municipalities were given verbal and written information about the study. The regional research ethics committee approved the study (Dnr. 434/03). None of the PRs was photocopied and all personal identification removed.

**Data analysis**

First, the extracted text from the PR and ITT was analysed using content analysis with the audit protocol as a coding scheme (Krippendorff, 2004). After this analysis, the same procedure was used to analyse the open answers from the nurses. The extracted texts were carefully read and sentences describing, e.g., patients’ swallowing was coded “swallowing difficulty”. Descriptions of eating difficulties that did not fit into the coding scheme were primarily coded ‘Other eating-related problems’. During the analysis, the ‘Other eating-related problems’ code was divided into 9 categories: appetite, assisted eating, chewing/oral problems, modified food consistency, “eats poorly”, “rejects food”, visual impairment/neglect, weight loss and tube feeding (table II). Because many notes were unspecific, the coding entailed elements of interpretation related to the stroke care context. To strengthen validity of the findings record data for three patients were analysed by a second reviewer, a RN experienced in auditing records. The findings were discussed until agreement was reached in the interpretation of the texts. Demographic data and frequencies of recordings were analysed using descriptive statistics.
RESULTS

At discharge from hospital, all patients had difficulties in at least three of the nine aspects of eating according to the MEOF-I screening, with one patient having difficulties in all nine aspects and one in eight aspects. Three patients had difficulties in seven aspects of eating, while four patients had six difficulties. The remaining six patients had five or fewer eating difficulties (Table I). No documentation of systematic screening in the PRs was found. Care planning related to eating difficulties, though not explicitly expressed as care plans, was present in six discharge summaries. According to documentation, all patients had been weighed at least once, with two losing considerable weight (one patient lost 8 kg and one lost 9 kg) during the care episode. The patients’ problems were described in non-specific lay language in the documentation.
<table>
<thead>
<tr>
<th>Gender</th>
<th>Age</th>
<th>Score</th>
<th>Total Discharge Summary</th>
<th>Destination</th>
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</thead>
<tbody>
<tr>
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<td>06</td>
<td>60</td>
<td>H</td>
</tr>
<tr>
<td>Male</td>
<td>87</td>
<td>06</td>
<td>80</td>
<td>H</td>
</tr>
<tr>
<td>Female</td>
<td>83</td>
<td>06</td>
<td>70</td>
<td>M</td>
</tr>
<tr>
<td>Male</td>
<td>90</td>
<td>03</td>
<td>80</td>
<td>H</td>
</tr>
<tr>
<td>Female</td>
<td>90</td>
<td>03</td>
<td>90</td>
<td>M</td>
</tr>
<tr>
<td>Male</td>
<td>88</td>
<td>03</td>
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<td>H</td>
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<tr>
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<td>80</td>
<td>09</td>
<td>80</td>
<td>H</td>
</tr>
</tbody>
</table>

**Table 1.** Gender-specific values for undernutrition, types of eating difficulties, need for assisted eating, and modified food consistency in stroke patients discharged from a municipality care (n = 15) as identified by MNA-SF and MEFO-I, and by audit of discharge summaries.

MNA-SF: Mini Nutritional Assessment Short Form (Rubinstein et al., 2001).

MEFO-I: Minimal Eating Observation Version 1 (MEFO-I, Westergren et al., 2008).
Accuracy in documentation of eating difficulties compared with patients’ status

The main types of information transfer at discharge were electronic for all 15 patients and telephone reports for 11 patients. Care planning conferences at hospital were carried out for six patients. At discharge from hospital, the ITT held information on eating difficulties with varying degrees of comprehensiveness for 11 patients. Nine discharge summaries from physicians had eating-related information, mostly on swallowing (four patients) and energy to complete a meal (three patients) (Table II).

As displayed in Table II, accuracy in documentation was inadequate with several aspects of eating difficulties missing when compared with the observation of patients’ status. The MEOF-I showed that the two eating difficulties most frequently documented were those related to swallowing and lack of energy to complete a meal. These two eating difficulties were also described in some of the discharge summaries and were acknowledged by municipal nurses two weeks after discharge. At discharge from hospital, all patients but one had difficulties with manipulation of food on the plate, but such difficulties were described in the PR for only 1 of the 15 patients. All patients had deglutition difficulties with swallowing and manipulation of food in the mouth (Table I). Fourteen PRs contained information on some aspect of those difficulties. Swallowing difficulty was the only problem described in all data sources during the information transfer process, but this occurred for only one patient. Lack of energy was described in all data sources except one, but for only one patient. At discharge from hospital, 13 patients had difficulties in one or more aspects of energy. The aspect ‘eats < ¾ of a portion’ was observed in 10 patients at discharge, but was only noted in two PRs and was not present in any discharge summary.
**Table II.** Eating difficulties and related problems among stroke patients discharged to municipal care as described in patient records, written information transferred and nurses’ descriptions of patients’ eating behaviour two weeks after discharge (n=15).

<table>
<thead>
<tr>
<th>Variables</th>
<th>Identified eating difficulties</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>&lt; 70 years</td>
<td></td>
</tr>
<tr>
<td>≥ 70 years</td>
<td></td>
</tr>
<tr>
<td>Gender, women</td>
<td></td>
</tr>
</tbody>
</table>

**Eating difficulties regarding**

<table>
<thead>
<tr>
<th>Ingestion</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Sitting position</td>
<td>8 7 2 2</td>
</tr>
<tr>
<td>Manipulation of food on the plate</td>
<td>14 1 1</td>
</tr>
<tr>
<td>Transport of food to the mouth</td>
<td>12 2 1</td>
</tr>
</tbody>
</table>

<table>
<thead>
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<th>Deglutition</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Open/close lips/leakage</td>
<td>5 3 1</td>
</tr>
<tr>
<td>Manipulation of food in the mouth</td>
<td>12 5 1</td>
</tr>
<tr>
<td>Swallowing</td>
<td>12 13 4 3 2 4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Energy</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Eating ¾ or less of a portion</td>
<td>10 2 1 3</td>
</tr>
<tr>
<td>Energy to complete a meal</td>
<td>11 10 3 3 1 2</td>
</tr>
<tr>
<td>Aberrant eating time</td>
<td>2 1 2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other eating-related problems</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Appetite</td>
<td>1 1 3</td>
</tr>
<tr>
<td>Assisted eating</td>
<td>12 3 9 8 9</td>
</tr>
<tr>
<td>Chewing/oral problems</td>
<td>1 3 2</td>
</tr>
<tr>
<td>Modified consistency</td>
<td>3 7 6 8</td>
</tr>
<tr>
<td>‘Eats poorly’</td>
<td>12 2 2 5</td>
</tr>
<tr>
<td>Rejects food</td>
<td>1 1 1 2</td>
</tr>
<tr>
<td>Visual impairment/neglect</td>
<td>2 1 4 4</td>
</tr>
<tr>
<td>Weight loss</td>
<td>1 1</td>
</tr>
<tr>
<td>Tube feeding</td>
<td>2 2 2 1 1</td>
</tr>
</tbody>
</table>

1 Described by Minimal Eating Observation, version 1 (MEOF-I, Westergren et al, 2008)
Accuracy of information transfer as perceived by municipal nurses

As in the PRs, municipal RNs and ANs described patients’ eating difficulties in lay language. RNs and ANs’ descriptions of patients’ eating difficulties focused primarily on nursing interventions, such as need for assisted eating and modified food consistency. However, ANs described eating in a comprehensive manner, often addressing patient participation. To illustrate, one example is cited:

He just doesn’t want to eat. He doesn’t say that the dishes taste bad, or that he cannot eat. He doesn’t complain; he just doesn’t want to eat. We have assessed his mouth and tried without his denture, but it’s the same. He can eat rye bread and cookies, indicating he has no swallowing problems. We accompany him at meals to encourage him, but it makes no difference.

After discharge from hospital, the situation, as perceived by the nursing staff, differed for some of the patients in comparison with the discharge summary. Four patients were reported to have oral problems, problems which were not previously recognised in the PR. Another four patients were assessed as having visual impairment that made mealtime activities complicated, but this was not recognised in the information that was transferred. Four patients were assessed to have better eating ability than was expected from the discharge information.

RNs and ANs’ perceptions of the information transferred are presented in Table III.

Table III. Accuracy of information transferred to municipal care as perceived by registered and assistant nurses (n=30).

<table>
<thead>
<tr>
<th>Variables</th>
<th>Registered nurses</th>
<th>Assistant nurses</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sufficient</td>
<td>5</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Fair, but some information missing</td>
<td>5</td>
<td>7</td>
<td>12</td>
</tr>
<tr>
<td>Insufficient information</td>
<td>3</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>No information</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Wrong information</td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Don’t know</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>15</td>
<td>15</td>
<td>30</td>
</tr>
</tbody>
</table>
For 10 patients, discharge summaries held extensive text on eating-related care and needs; on the other hand, five summaries contained little or no such information. For these 10 patients, the RNs expressed that they had received sufficient or fair information, except in one case. The ANs perceived that they had received sufficient information for only two of those patients, fair information for seven patients and wrong and insufficient information for one patient. Because the RNs and ANs perceived that discharge information was not always accurate, they reported that they often made their own assessments in identifying each patient’s individual needs on how he or she could manage their eating.

Three eating-related problems not included in the MEOF-I were frequently described in PRs, discharge summaries and in the descriptions of the RNs and ANs: the patient “eats poorly”, “needs assisted eating” and “needs modified food consistency” (Table II). Information on patients’ eating ‘poorly’ without a specified aetiology was found in 12 PRs and four discharge summaries. Need for assisted eating without further explanation was noted in 12 PRs and 12 discharge summaries. Eight RNs and nine ANs described patients’ need for assisted eating. Need for modified food consistency was described by six RNs and eight ANs and was noted in seven discharge summaries, but only in three PRs. Weight loss was identified in one PR for a patient who had lost eight kg in 79 days but information was not included in the discharge summary. For the same patient, descriptions of his tube feeding occurred in all the data sources.

DISCUSSION
All patients had multiple eating difficulties and were at risk for undernutrition and thus in need for care planning to prevent further deterioration. One single patient had no ingestion problems, that patient was also the only one who was discharged home. Discharge summaries
in 10 patients held extensive text. That information was also judged as either sufficient or fairly sufficient by most of the receiving RNs. Several eating-related problems not included in the discharge information were reported by RNs and ANs in municipal care after discharge. Similar results have been presented by researchers in other contexts, such as absence of report on pressure ulcers in discharge summaries (Gunningberg et al, 2000) and on district nurses’ dissatisfaction with discharge information (McKenna et al, 2000).

No signs of a systematic assessment of patients’ eating difficulties were found in the PRs. The assessment of physical functions (such as mobility), however, were carefully documented. In patients with potential need for extensive continuing care the need for strategies to prevent complications and avoidable suffering is obvious. In order to identify patients that require nutritional interventions, screening for such risk is an essential first step in a process of nutritional care. For stroke patients, the systematic observation of eating (MEOF-I) not only elicits all the aspects of eating difficulties but can also predict length of hospital stay and the extent of further care needs (Westergren et al, in press). The 15 patients in the study were all at risk for undernutrition. Despite this fact, no plan for long-term nutritional care was identified. Patients were weighed in the stroke unit, but in only one case did a substantial weight loss lead to interventions ordered by a dietician. However, it has been suggested that regular weighing of patients is an important step in identifying risk patients, where a weight loss of 3 kg or more indicates the need for nutritional assessment (Jönsson et al, 2008).

Another study stressed the importance of giving patients with low energy and poor appetite protein- and energy-enriched food and nutritional supplements in order to prevent undernutrition from developing (Westergren et al, in press). In the present study the four patients who were discharged to rehabilitation units showed signs of nutritional deficiency and three of these patients had low energy (Table I). Thus, systematic weighing of patients,
structured screening for nutritional risk and assessment of eating ability are necessary if these problems are to be dealt with in a thorough way. Adequate nutrition is pivotal in meeting the patient’s rehabilitation needs. Positive results have been reported from intervention studies on energy-dense meals (Ödlund Olin et al, 2003), use of a food and meal policy (Kousma et al, 2008) and staff priority of mealtime support for older patients (Dickinson et al, 2007).

In several patients the most extensive information (although not very comprehensive) on their eating difficulties was found in the ITT. However, all RNs in municipal care did not have the routine to read electronic information despite that they used an electronic PR. Thus, many RNs in municipal care still relied on traditional forms of information. However, the web-based ITT system and the municipal electronic PR system were not compatible. Several studies have shown that, even in the ‘electronic era’, RNs have insufficient knowledge in searching information in electronic systems (Björvell et al, 2002). To accomplish reliable informational and management continuity for patients with stroke and eating difficulties ITT and other electronic tools need to be developed to contain not only unstructured discharge information, as was found in the present study, but also be part of an integrated PR with relevant decision support for nursing staff. For example, Scandurra (2007) proposed an electronic application for sharing information between health care professionals, the patient and next of kin, and based on point of care accessibility and integration of information from different care providers. For such devices to be successful, RNs and other health care professionals need to acknowledge their usability. Information in the PRs and discharge summaries in our study was not only unstructured but also the terminology used was unspecific and inconsistent, which confirms earlier findings (Kumlien & Axelsson, 2002; Kim & Park, 2005). In addition to the lack of identification of nutritional risk, recordings and interviews indicated insufficient knowledge on nutrition and eating difficulties (e.g., vague
STUDY II

Little knowledge exists thus far on how transfer of information and responsibility for further care planning between levels of care are processed (Hellesø et al., 2004), as well as on the appropriate and relevant content of that information to accomplish information and management continuity. One aspect of continuity of care, which, to our knowledge, has not been revealed previously, was the discrepancy between how transferred information was described by RNs and ANs, with ANs claiming that they receive sufficient information for only two patients. Moreover, ANs described that they often relied on their own assessments of the patients’ needs and not on the information they obtained from other health care professionals.

Inadequate information transfer and “gaps” in information from hospital to municipal care are a threat to patient safety (Boockvar & Burack, 2007). Thus, important prerequisites for continuity of care are unambiguous and standardised assessment and outcome indicators, expressed in terminology that can be understood by all health care professionals. Furthermore, the information transfer process needs to be coherent. In the specific area of eating and nutrition our findings show that important aspects of eating difficulties seem to remain unrecognised because of the absence of systematic screening. In older patients with stroke, often aggravated by communication deficits, coherent care in the transfer from hospital to municipal care is imperative.

STUDY LIMITATIONS

Information is the common thread linking care for the individual from one care provider to another. This information may be contained in a health care professional’s memory, on paper or in electronic media. This fact is important to keep in mind when searching for information on the care that has been provided. We studied information transfer and continuity of care by
screening patients’ state, auditing PRs and discharge summaries and by interviewing receiving RNs in municipal care. All RNs expressed the view that the telephone report from the hospital nurse at discharge was an important source of information. This verbal information transfer, however, has not been included in our study. Another fact to keep in mind is that data were collected in different phases of the patients’ illness trajectory: PR data represented the entire hospital care episode, sometimes extending over several weeks and screening of eating ability was made close to discharge representing the state of the patient at discharge. Finally, the interviews were performed two weeks after discharge of the patients. In this way nurses in the receiving municipalities were expected to have had reasonable time to assess the patients’ eating ability and nutritional needs. Accordingly, eating difficulties, as described in the PR, could have declined at the time of discharge but, nevertheless, it would have been relevant to include for prediction of nutritional risk in the discharge summary. A possibility exists that the problems that were unrecognised in the PR but described by nurses in the municipalities could have developed during the one to two weeks after discharge. However, this is not likely because visual impairment and problems with chewing are problems of a persisting nature that probably take some time to develop.

This study used a limited sample because of the complex data collection process with its scheduled time sequences for gathering all data. To further study information transfer between care providers repeated assessments of eating, observations of care planning conferences and information transfer by telephone could be included to gain a more comprehensive picture of the information transfer at discharge.

CONCLUSION

Informational continuity and accuracy of information on patients’ eating difficulties were poor, as was accuracy in the transferred information of eating difficulties according to
nursing staffs’ perceptions. All patients were at risk for undernutrition and in a poor state to receive rehabilitation. Nevertheless, patients’ eating difficulties were described in a vague and unspecific language. Co-ordinated care planning and management continuity related to eating difficulties were largely lacking in the documentation. Despite their important role in caring for patients with eating difficulties, little information on eating difficulties seemed to reach ANs in the municipalities. These ANs instead tended to rely on their own judgement of patients’ eating ability.

ACKNOWLEDGEMENT

The study was supported by the county council of Örebro, Sweden.

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Manuscript EC, ME, AE
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Stroke and eating difficulties: long-term experiences

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Submitted for publication: 6 January 2004
Accepted for publication: 19 May 2004

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Background. Previous studies have shown that eating difficulties after stroke are common and often associated with communication problems. These difficulties, however, have mainly been studied from a professional perspective. Although numerous aspects of dysfunction have been identified, little knowledge exists about the experiences of living with eating difficulties.

Aim. To explore how people affected by stroke experience living with eating difficulties, during a prolonged period.

Design. Explorative, qualitative case study.

Methods. Repeated interviews and participant observations with three persons 1.5–2 years after their last stroke. Data were analysed using qualitative analysis.

Results. Eating difficulties after stroke were experienced as Striving to live a normal life, with the subthemes Abandoned to learn on one’s own, Experiences of losses and Feeling dependent. The process of getting back to a life that resembled life before the stroke was experienced as long-lasting and hard work. The informants felt that they were abandoned to manage eating training on their own. The informants experienced a loss of functional eating ability and the ability to perform activities related to food and meals. Feelings of dependence were experienced in mealtime situations.

Conclusion. Living with eating difficulties after stroke is a complex phenomenon. The informants felt abandoned because of lack of support from the nursing staff. They were left on their own to deal with the difficult process of adjusting to a new way of eating and losses regarding mealtime activities. The combination of repeated interviews and participant observations seemed to be an approach that should be tested in larger studies.

Relevance to clinical practice. This case study indicates a need for nurses to develop and use evidence-based guidelines for eating training during the continuum of care. Nurses need to assess patient’s habits and desires related to eating, and to adjust environment according to patient preferences.
Introduction

Eating and drinking, which are governed by social, cultural, religious, geographical and economic factors, are fundamental activities in daily life (Mennell et al., 1992). Eating is often a taken-for-granted activity, despite the fact that it is a complex process requiring sensitive coordination of a number of motor and sensory functions (Perlman & Christensen, 1997). In everyday life, eating is defined as the consumption of food and liquid to sustain life. Several states of illness as well as the normal ageing process can cause eating difficulties (Nordström, 1990; McCormack, 1997). The ability to maintain deep-seated mealtime behaviours and roles also affect the eating process (Sidenvall et al., 1994; Gustafsson et al., 2003). Improper eating may result in malnutrition, failing health and, in its extreme form, a premature death (Chen et al., 2001; Isabel et al., 2003).

Stroke and eating

Stroke is one of the major illnesses which may cause eating difficulties. Stroke is the third leading cause of death in the Western world and the most common cause of disability in the developed countries (Peltonen & Asplund, 1996; Wolf & Á gostino, 1998). In Sweden, 25 000 patients suffer a stroke every year, whereof 20 000 are affected for the first time. The prevalence is estimated to be about 100 000. Of these, at least 20 000 need comprehensive nursing care and supervision 24 hours a day, often including assistance when eating (Socialstyrelsen, 2000b). Several aspects of eating difficulties have been identified in stroke patients; for example, problems related to handling food on the plate, transporting food to the mouth, chewing, swallowing and hoarding food in the mouth. Eating difficulties can also be related to lack of energy and aberrant eating speed. Dysphagia occurs in 19–50% of acute stroke patients, but has been found to resolve in many cases within 14 days (Wolfe et al., 1993; Westergen et al., 1999). Many stroke victims have more than one of these problems in addition to such difficulties as mobility and/or speech (McLaren & Dickerson, 2000; Westergen et al., 2001). Communication difficulties after stroke are common and may have different aetiology and manifestations. Speech difficulties (i.e. dysarthria) involve disturbances in the muscular and respiratory control of the speech mechanism and are often related to dysphagia. Eating difficulties may cause dehydration, malnutrition and aspiration and can lead to feelings of shame, dependency and other negative experiences (Axelsen et al., 1989; Unosson et al., 1994; Jacobsson et al., 2000; Ramsey et al., 2003). Several studies have been concerned with identifying and assessing eating difficulties, but only a few have focused on patient experiences of living with eating difficulties after stroke (Jacobsson et al., 2000; Perry & McLaren, 2003). In a Swedish study with 4000 persons 2 years poststroke, 7% reported a need for assisted eating (Socialstyrelsen, 2000a).

Experiences of living with eating difficulties after stroke

In a qualitative study with 26 persons suffering from acute stroke, Jacobsson et al. (2000) found the following categories of experiences of eating difficulties: fear of choking, discomfort in the mouth and throat, thirst, discomfort from food, shame about one’s appearance, humiliating dependency in eating and threat to hope. Perry and McLaren (2003) conducted interviews with 206 persons 6 months poststroke and found two main themes of experiences with eating disability: ‘getting back to normal’ and ‘getting by’. ‘Getting back to normal’ meant either a process towards life as it was before stroke or a new ‘normalized’ mode of eating, adjusted to the effects of stroke. ‘Getting by’ contained several aspects, including acceptance of modified texture diets and of aids and assistance to maintain social functions. Both studies combined semi-structured interviews with assessment of eating performance. To achieve representation of communication-impaired stroke survivors the authors included next-of-kin to be spokespersons.

In conclusion, eating is a complex and fundamental activity that has a great impact on the experience of ‘being a person’ in a social context. The experience of living with eating difficulties may vary depending on the phase of the illness trajectory. In the acute phase there is an emphasis on experiences of discomfort, fear and threat to hope (Jacobsson et al., 2000). After 6 months the experiences were twofold: a striving towards ‘normalized’ eating and a situation of ‘getting by’ (Perry & McLaren, 2003). To our knowledge, the experiences of stroke victims themselves, living with eating difficulties during a prolonged period, has not been studied previously. Therefore, it is crucial for the development of nursing of stroke patients to acquire a greater understanding and knowledge of the situation of these
individuals under different phases of their illness. The aim of the current study was to explore how persons affected by stroke experience living with eating difficulties during a prolonged period.

Method

In most qualitative studies, persons with communication disorders are excluded and therefore methods for gathering data of this group are not well developed (Quinn & Campbell, 1996; Kvigne et al., 2002). Recent research concerning care of patients with communication difficulties has revealed how skilled care professionals ‘invite the patient to participate in the creative act of communication’ (Sundin & Jansson, 2003, p. 107). This act is facilitated by a close and open inter-subjective relationship, as well as by observing and interpreting the patient’s body language (Sundin & Jansson, 2003). Inspired by Sundin and Jansson’s work, the present study design contains both repeated qualitative, open interviews and participant observations of meal situations to gain a deeper understanding of the phenomenon (Morse, 1994; Silverman, 2003). The study is a case study with three informants suffering from extensive eating difficulties. In this study, eating difficulties were seen in a context, including aspects like meal situations, cooking and food preferences.

Informants

The study was conducted in 2002 in a Swedish rural area with elements of farming, hunting and forestry. Personnel at a day care clinic at a local hospital were asked to identify stroke patients with eating difficulties. Three patients were identified at the clinic having some kind of eating difficulties. These patients were judged by the personnel to be able to communicate with the investigator, although all three had varying degrees of speech problems. The informants were:

‘Mr B’: a 68-year-old retired industrial worker. He lived with his wife in the same house as before the stroke. He could walk indoors with a wheeled walker. He had dysarthria that could be managed when he concentrated, spoke slowly and was well rested and calm.

‘Mrs S’: a farmers’ wife 82 years of age. She and her disabled husband had to leave their farm and move to a service accommodation for elderly when ‘Mrs S’ was discharged from hospital after her second stroke. She used a wheelchair. For 6 months she had a surgical gastrostomy and enteral nutrition. She had dysarthria, with a wet-sounding voice and frequent coughing when talking.

‘Mr O’: a 61-year-old taxi driver. He was divorced and lived alone in his secluded house. He used a wheelchair and had personal assistants provided by the municipality social service. He used to have a percutaneous endoscopic gastrostomy and enteral nutrition for 6 months after the stroke. He had dysarthria with whispering, slurred speech.

All the informants expressed worries that the investigator would not be able to understand their speech.

Ethical considerations

Interviewing and observing persons suffering from chronic illness and loss of bodily functions are demanding tasks requiring sensitivity and tactfulness. Because the persons in this study also had communication problems, it was even more important to give careful information about the study and to be sensitive to any signs of the person wanting to withdraw from the interview. The investigator (the first author) had a long experience as a nurse caring for older people and was familiar with communicating with persons suffering from speech problems. The personnel at the day care clinic were informed about the study and were able to support the informants if they showed signs of emotional distress after the interviews. The Research Ethics Committee, Örebro County Council approved the study (Dnr 1170/01).

Data collection

The three informants received information letters describing the study and the voluntary nature of participation. All three patients agreed to take part in the study. The investigator visited the persons individually to provide additional information about the study. This dialogue also had the purpose of determining whether the investigator could understand the speech of the informants. No assessment of cognitive skills was made. ‘Mr B’ and ‘Mr O’ were interviewed in a conference room at the day care clinic and ‘Mrs S’ was interviewed in her home, according to their own choices.

The first interview was carried out about 1.5 years after discharge from the stroke unit. It lasted about 60 minutes. All interviews were tape-recorded. To help the informants focus on the phenomenon of interest, the opening question was: ‘Do you remember when you were at the hospital and first realized that you could not eat like before?’ An interview guide was constructed based on the aim of the study and earlier research though the investigator tried to be as open as possible to the narratives of the informants. All three informants had dysarthria in addition to their eating difficulties, making it hard for them to express their thoughts in long sentences and rich narratives. Their speech was partly difficult to understand, even for a nurse experienced in caring for older people. To get rich descriptions the investigator

tried to create an open, communicative attitude, using summaries of what had been said and asking ‘I understood that what you said was... Is that right?’ The investigator also observed and made notes of the non-articulated language expressed by the informants’ body language (Kvigne et al., 2002).

The second interview was conducted 3 months after the first one. On this second occasion, the investigator invited the informants to have a light meal with coffee/tea, bread and butter. The informants had been informed that the investigator was going to observe the eating process. Observations from the meal situation were recorded in field notes by the researcher during and immediately after the meal (Kvigne et al., 2002). The participant observation and the second interview each lasted between 40 and 60 minutes. The field notes were used and analysed together with the transcripts.

Setting
To illustrate the context for the interviews and observations, the example of an afternoon snack together with ‘Mr O’ is presented. He had been to the Department of Physiotherapy for hydrotherapy, which left him a bit cold and spastic in his left arm. He sat in his wheelchair with the left arm wrapped in towels. His personal assistant put butter on the bread and made a cup of tea for him, but ‘Mr O’ stressed that he could do that himself if he had to. We talked about his rehabilitation and what had happened since we last met. ‘Mr O’ was eager to tell, but had to stop talking and concentrate on chewing and swallowing when he had food in his mouth or when he was drinking tea. He dipped the bread into the cup before putting it in his mouth and bent his head carefully forward when swallowing. It had become a habit to do these things when eating. ‘Mr O’ told me that he still had problems swallowing and that he often choked when eating, but he no longer had intensive coughing attacks as he used to have. He reported that his chewing problems had worsened because of denture problems.

Data analysis
Data analysis started in the interview situation itself (Morse, 1994; Kvigne et al., 2002; Silverman, 2003). The investigator attempted to make the informant clarify the meaning of what was said. This was especially important in that the speech of the informants was hard to understand. For the same reason, the investigator was open for the body language of the informant. All audio-taped interviews were transcribed verbatim promptly after the interviews. These transcripts were an important part of the data analysis, serving as a tool for interpreting what was said during the interviews (Morse, 1994). During the first interview, some preliminary themes emerged from the informants’ stories. In the second interview the investigator sought to obtain a richer description and confirmation that she had understood the statements according to the informants’ point of view. The procedure of analysis has been inspired by phenomenological tradition and can be described in five steps (Giorgi, 1985; Kvale, 1996):

1. A naive reading of the whole text and simultaneous listening to the tape-recorded interviews. For each informant, the field notes and both interviews were analysed together. The purpose was to obtain a sense of the whole, both the spoken language and the non-articulated as represented by the field notes.

2. Natural meaning units were extracted from the texts. These units often consisted of the investigator’s question, the answer from the informant and a new, confirming question from the investigator. Key words were extracted from the field notes.

3. Formulating the statements that dominate the meaning units and observation notes into preliminary themes was made, using the question: ‘What does it mean to live with eating difficulties after stroke?’

4. Refining the preliminary themes by moving back and forth between the research question, the texts and the audio-tape until a more abstract expression of the theme was synthesized.

5. Bringing together the themes from the three informants and weaving together the central themes into a descriptive statement.

Examples of meaning units, preliminary themes and subthemes are shown in Table 1a–c.

Trustworthiness
Validation in qualitative research is a process of continually checking, questioning and theoretically interpreting the findings (Kvale, 1995; Morse et al., 2002), or a question of trustworthiness (Lincoln & Guba, 1985). ‘Checking’ the findings, or steps to improve credibility, included careful efforts to ensure that the speech of the informants was properly understood. After formulating the first, preliminary themes, the investigator returned to the informants to verify that she had understood their statements correctly. The informant also had an opportunity to elaborate further on the emerging themes with the purpose of expanding the depth and validate the emerging analysis. All authors took part in formulating the interview guide, listening to the audiotapes, extracting meaning units and formulating themes. To improve transferability the description of the context and
### Table 1 Examples of selected meaning units, preliminary themes and subthemes related to the theme *Striving to live a normal life*

<table>
<thead>
<tr>
<th>Meaning units</th>
<th>Preliminary themes</th>
<th>Subtheme</th>
</tr>
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<tbody>
<tr>
<td>(a) R: I remember that I felt panic, I felt panic. I: Was that when they came with the spoon, and were going to put food in your mouth? R: Yes! I: Were you able to make the nurse understand? R: No! – The same when you got water to drink, it was the same too. I: You felt panic? R: Yes! I: That must have been hard to experience. R: Yes, I felt really deserted</td>
<td>Expresses feelings of panic and of being deserted when being fed</td>
<td>Abandoned to learn on one’s own</td>
</tr>
<tr>
<td>I: You still have difficulties closing your lips properly? R: Yes I: But you can eat ordinary food? R: Yes, I eat just ordinary food I: And your swallowing problems have declined? R: Some of it, but not totally, no, not totally I: Do you have to take certain precautions when you’re going to eat? R: Yes, if I am going to drink coffee, I have to remember to keep the mouth shut – I have to pinch together the lips – but it doesn’t always work, sometimes coffee will spatter, from the mouth – all over the table. I: You have to really concentrate when you’re eating? R: You bet!</td>
<td>Describes difficulties to swallow and to keep lips closed when swallowing, and how he has to concentrate on this when he is eating</td>
<td></td>
</tr>
<tr>
<td>(b) R: Well, in the morning we have coffee and a sandwich. Yes, something like that… I: Can you reach things from the wheel chair, to make coffee and lay the table and so? R: No, my old man has to do that I: So he has to do that? R: Yes… I: You have to help one another? R: Yes, otherwise it wouldn’t work… you know I cannot… it’s the sink, it’s too high. I: It hasn’t been adjusted to your wheel chair? R: No, it hasn’t I: So you just sit here and tell him what to do (laughing)? O’yes! And then he gets mad (laughing)! I: It sounds as if you have adapted quite well to all the problems you described, or do I misinterpret? R: Well, quite… quite, but it’s still hard… well I say, I have to chew the food so damn much. There mustn’t be any whole bits. Not like before when I eat everything, mixed together, I eat anything! I: One doesn’t realise there are so many elements in eating? R: Yes, there are</td>
<td>The spouse has to do the kitchen work. R cannot do anything in the kitchen because of lack of home adjustment</td>
<td>Experience of losses</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Earlier he could eat anything without reflecting on it</td>
</tr>
</tbody>
</table>
the observations were written as ‘thick’ as possible (Lincoln & Guba, 1985). To improve confirmability, data collection, interpretation of the data and preliminary findings were discussed in two research seminars, as well as at a national nursing conference workshop with expert researchers and nurses experienced in stroke care.

Findings

The findings of this study emerged into one major theme Striving to live a normal life, and three subthemes Abandoned to learn on one’s own, Experience of losses and Feeling dependent. In the next section the main theme and the three subthemes are presented and illustrated by meaning units from the interviews.

Striving to live a normal life

The overall theme Striving to live a normal life emerged from the three subthemes. The process of getting back to a life that resembled life before the stroke, or a new kind of ‘normalized life’, was experienced as a long-lasting process that required hard work.

Abandoned to learn on one’s own

The informants expressed feelings of being largely left on their own to re-learn and adjust to a new life situation. Further, the informants experienced a lack of adequate knowledge among the nursing staff about how to help the patient with eating difficulties. Relearning to eat was something that the informants perceived as a task that they had to handle mostly on their own. Eating training, practical advice and support in the meal situation were rare at the hospital. The learning process was one of ‘trial and error’, where the informants had to show endurance and discover on their own how swallowing was best managed, what foods they could tolerate, which dietary texture was the best and what body position was the most functional. The speech therapist had given some practical advice, but the stroke victims themselves had to learn to adapt this advice to their unique situation. The pureed food texture provided at the hospital was successively replaced by a

<table>
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<tr>
<th>Meaning units</th>
<th>Preliminary themes</th>
<th>Subtheme</th>
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<tr>
<td>(c) I: I can see that you don’t have any problems with weight loss R: No, yes in one way! I: Perhaps you eat too much? R: Yes... I: Is that a problem for you? R: Yes it is. I get too heavy for my personal assistant to move (to the wheel chair). I mustn’t weigh over 70 kilograms! I: I suppose that’s reasonable. Can you stand without support? R: No I can’t</td>
<td>He must restrict eating so that he doesn’t get to heavy for the personal assistant to move</td>
<td>Feeling dependent</td>
</tr>
<tr>
<td>I: You told me earlier about the adjustment of your home... R: That’s not finished yet! I: The bathroom isn’t finished yet? R: Well, I suppose I’ll have to accept it…. But the floor is too.... I can’t move to the wheel chair on my own! I: And that makes you more dependent? R: Yes! (sounds upset) I: There were no plans on adjusting the kitchen? R: No, no! I: You were not supposed to be cooking since you have your personal assistant? R: No! (sounds upset) I: But you can make yourself a sandwich? R: Not in the kitchen...</td>
<td>He is upset over delayed and incomplete home adjustment, making him unable to use his kitchen and more dependent on others than he could have been</td>
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text that was more like regular food. After 18 months the informants could eat almost everything they wanted and needed no assistive devices in the meal situation. Some one else had to cut and prepare the food on the plate and only one hand was used when eating, often with a spoon. Concentration was vital for management of the bolus in the mouth and for swallowing safely, as illustrated by the quotations in Table 1a. The fear of choking when swallowing had successively faded, but the informants were aware of how frightening a choking attack could be for the other persons at the table. Other problems when eating were spilling and coughing. The informants did not experience any improvement of eating ability after discharge.

Experience of losses

Two kinds of losses that informants described were related to eating difficulties: loss of functional eating ability and loss of ability to perform valued or established activities related to food and meals. Loss of bodily functions ranged from the panic that ‘Mr O’ experienced when he realized that he could not swallow in the acute phase of his hospital stay to hemiparesis, inability to move, heavily decreased sensitivity in mouth and hand, difficulties in chewing and handling food in the mouth, loss of body weight and loss of speech. One example is ‘Mr B’s’ recollection of his condition from the first time at hospital:

R: And water, it wasn’t possible to drink.
I: How did you feel about that?
R: It was hard, yes it was hard.
I: Was that immediately when you got sick?
R: Yes, but it prepared so I can get them in the fridge.
I: And you can make yourself a cup of coffee or go to the bathroom?
R: Yes, she prepares sandwiches so I can get them in the fridge. (‘Mr B’)

Not being able to continue with valued activities was a hard situation for the informants. ‘Mrs S’ had been a housewife for a long time; ‘Mr B’ had used much of his spare time to work in the garden growing vegetables; ‘Mr O’ was a hunter and used to spend considerable time in the woods hunting or picking wild berries. Both the men had enjoyed cooking. The kitchen had been a familiar milieu where much time was spent before their stroke. Now the ability to take part in any household activities was severely limited because of lack of home adjustment, as the following quotation illustrates.

Added to all the other heavy losses that the informants had to deal with, these losses resulted in their lives being less eventful than before their stroke, making them more or less dependent on others. Table 1b shows quotations illustrating these experiences.

Feeling dependent

In mealtime situations the informants were dependent on others. This was partly due to their hemi-paresis and partly due to a lack of home adjustment. ‘Mr B’s’ situation is an example of this meal-related dependency:

I: Can you manage on your own so that your wife can go away occasionally?
R: Yes, she can go away and be a babysitter now and then – it works fairly well.
I: And you can make yourself a cup of coffee or go to the bathroom?
R: Yes, but she prepares sandwiches so I can get them in the fridge. (‘Mr B’)

Dependence in mealtime situations was only one aspect of the dependency that the informants expressed. There was also a lack of self-care capacity in other activities of daily living including hygiene, getting dressed and mobility. Having a stroke, which left these persons physically disabled and speech impaired, also had an effect on their social roles. All three persons had in some way been active in acquiring, preparing and cooking food. Eating had been a taken-for-granted activity. After stroke, the mealtime situation became replete with new problems, including coughing, spilling, dribbling and not being able to handle food properly on the plate or in the mouth according to what is culturally acceptable. The informants had all been active, hardworking individuals and this dependency on others meant a shift to a new role in the family. ‘Mrs S’, who had been a housewife for 50 years, now had all her meals except breakfast in the restaurant at the sheltered housing. Her disabled husband managed to make breakfast for his wife and himself and helped her to go with the wheelchair to the restaurant. Another aspect of dependency was being dependent on social authorities regarding rehabilitation, housing adjustment and personal assistance. The informants expressed many problems, but they also expressed that their families and friends were indulgent towards their coughing, spilling and dribbling. ‘Mrs S’, who was older than the men, expressed a sense of gratitude for each day that she was alive, whereas the men mostly expressed feelings of frustration and loss. The speech impairment was described to be the hardest to cope with.

Aspects of feeling dependent are illustrated in Table 1c.

Discussion

The most striking impression from the dialogues with the informants was their constant struggle to re-create a normal life. This trajectory contained a relearning-to-eat process, a process of dealing with several losses and a process of adjusting to different aspects of dependency. Striving to live a
normal life contains many features of the illness trajectory described by Kirkevold (2002) but also other, more specific features. Kirkevold proposes that the adjustment process after stroke can be divided into four phases: a trajectory onset phase, an initial rehabilitation phase, a continued rehabilitation and a semi-stable phase. The semi-stable phase lasts approximately six months to a year or more after stroke onset. It is characterized by (i) going on with life while adjusting for the long-term effects of stroke, (ii) resuming/ (re)forming valued activities and (iii) trying to minimize the effects of stroke on life and on self (Kirkevold, 2002, p. 892).

In the semi-stable phase of adjustment the stroke victims begin to realize that life will not return to what it was before the stroke. The aim of the current study was to explore how persons affected by stroke experience living with eating difficulties over a prolonged period. The informants’ description of their life situation is comparable with a description of the semi-stable phase, but where the focus is primarily on eating. They showed that adjustment to severe eating difficulties is exceedingly difficult, but that it is possible to adjust to and develop new structures for valued activities as they strive to live a normal life. Compared with the studies by Jacobsson et al. (2000) and Perry and McLaren (2003) the current study implies that ‘living with eating difficulties after stroke’ is experienced quite differently in different phases of the illness trajectory. In the acute phase there is an emphasis on experiences of discomfort, fear and threat to hope (Jacobsson et al., 2000). After six months the experiences were twofold: a striving towards ‘normalized’ eating and a situation of ‘getting by’ (Perry & McLaren, 2003). The informants in the current study had come further in their trajectory and had more or less accepted that life was like this. This process of adjustment to a totally different life situation could also be compared with ‘the drama of suffering’ with the three acts: ‘confirming’ where the sufferer is longing for the suffering to be confirmed, ‘being in suffering’ where the sufferer needs time and space to suffer, and ‘becoming in suffering’ where the sufferer wants to become reconciled and develop a new sense of wholeness (Lindholm & Eriksson, 1993).

Abandoned to learn on one’s own was one of the subthemes that emerged from the data. Lack of knowledge about safe eating techniques among the nursing staff, and lack of support for eating training was strongly experienced by the informants. Other authors (Jacobsson et al., 1997; Steele et al., 1997) have described this experience as well. The subtheme contains several aspects that are similar to those presented by Hamilton (2000), who found that living with stroke is a process of learning by experience. The author studied how life three years after stroke was described using a phenomenological approach. Although the phenomenon of eating was not in focus and in fact was hardly mentioned in the thesis, Hamilton found that the informants strived to maintain identity, integrity and autonomy, which are basic values in a normal life. In this study, several aspects of trying to maintain those fundamental values in relation to eating were expressed.

The subtheme Experience of losses was described as the loss of skills necessary for eating and of activities related to food and eating in a specific context, such as cooking or picking wild berries. Mumma (2000) found that persons with stroke perceived two major losses, namely, loss of mobility and loss of independence. Eating ability, however, was not mentioned. In this study, the losses that the informants expressed could be part of the loss of independence as well as the loss of mobility. The informants also expressed grief over losses that they understood were irrevocable.

There is a close relationship between losses and dependence, with the latter often being a consequence of the former. Feelings of dependence after stroke has been described as a serious problem for stroke victims (Åström et al., 1991; Jacobsson et al., 1997; Hamilton, 2000). Jacobsson and co-workers found ‘feeling dependent’ as one of the life consequences arising from eating difficulties. From a nursing perspective, individualized intervention programmes can significantly affect the feeling of dependence/independence in mealt-time situations. A new social role emerges from the different problems and impairments after stroke. ‘Mrs S’, who was 82 years old, did not react much towards being dependent and disabled. She lived one day at a time and did not expect to live that much longer. Both of the male informants were younger and expressed frustration with learning to cope with their changed roles.

The findings of the present study contribute new knowledge to that presented by Jacobsson et al. (2000) and Perry

![Figure 1 Possible trajectory of experience of living with eating difficulties after stroke.](image-url)
and McLaren (2003), demonstrating that life with eating difficulties after stroke is experienced differently depending on the point in time of the illness trajectory (Fig. 1).

Methodological considerations

Persons with speech problems are often excluded in qualitative interviews. Trying to develop methods to describe experiences from an insider perspective is an important task for nursing research. In this case study, we tried to create a method for gathering data from informants with speech problems. A limitation of the study is that dependability has not been examined although the process of data collection and analysis is described in detail (Lincoln & Guba, 1985). The findings are the result of the analysis process handled by the researchers. Other researchers might have come to other conclusions. However, the combination of efforts to get to know the informant, repeated interviews and participant observations seems to be a useful way of collecting data from this group of patients. Despite repeated interviews, the informants’ stories were not very rich in information. An ethical issue worth considering is the close relationship between informant and investigator that might develop during the process of data collection. Other approaches to data collection would have been video-recordings combined with interviews or an ethnographic design. Video-recording of vulnerable persons, however, raises many ethical questions and was therefore rejected. The preunderstanding of the investigator, in this case long experience as a nurse caring for older people, could have influenced the study in both a positive and negative fashion. The positive component is that the investigator is familiar with communicating with persons with speech problems, as well as with the milieu and procedures at a stroke unit. The negative component is that this preunderstanding may result in the investigator being less sensitive to the narratives of the informants and that the informants regarded her as ‘one of the staff’. However, as the informants expressed criticism of the nursing care system, this was seen as an expression of trust in the investigator.

Implications for nursing

The current study showed that eating difficulties after stroke from an insider perspective is a complex phenomenon. It contains not only physical, perceptual and cognitive factors, but also social, psychological and existential ones. The informants felt abandoned because of the nursing staff’s lack of adequate knowledge on how to manage eating training. Surprisingly, these important aspects of caring are even neglected in the Swedish national guidelines for stroke care (Socialstyrelsen, 2000a) and pathways for stroke care (Irwin, 1996). By tradition, eating and feeding are taken-for-granted activities and specific nursing knowledge in these areas is sparse, even in the care of severely impaired stroke patients. Training of dysphagic patients has mainly been managed by speech therapists. Because functional eating behaviour is a complex and multi-dimensional activity, eating training requires a holistic approach and evidence-based methods (Ramritu et al., 2000). Jacobsson and co-workers have shown that individualized assessment and eating training after stroke could improve eating ability (1997) and be extremely cost effective (2000). For the security and well-being of stroke patients, there is a strong need for evidence-based clinical guidelines that are readily accessible at the point of care. Stroke patients with eating difficulties are a vulnerable group, a group that is clearly at risk for various complications related to their eating difficulties. To develop clinical guidelines that comprise all the components of living with eating difficulties, from the patients’ perspective, nurses have to learn more about the experiences of these patients and to apply research findings to clinical practice.

Acknowledgements

The study has been financially supported by Strokeförbundet (the Swedish Stroke Association) and by the County Council of Örebro, Sweden.

Contributions

Study design: EC, ME, AE; data analysis: EC, ME, AE; manuscript preparation: EC, ME, AE.

References

E Carlsson et al.


STUDY IV
Methodological Issues in Interviews Involving People With Communication Impairments After Acquired Brain Damage

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Qualitative research has made a significant contribution to the body of knowledge related to how people experience living with various chronic diseases and disabilities; however, the voices of certain vulnerable populations, particularly those with impairments that affect their ability to communicate, are commonly absent. In recent years, a few researchers have attempted to explore the most effective ways to ensure that the voices of people with communication impairments from acquired brain damages can be captured in qualitative research interviews; yet several methodological issues related to including this population in qualitative research remained unexamined. In this article, the authors draw on insights derived from their research on the experiences of adult survivors of stroke and traumatic brain injury to describe methodological issues related to sampling, informed consent, and fatigue in participant and researcher while also making some recommendations for conducting qualitative interviews with these populations.

Keywords: communication impairment; qualitative research; interviewing; informed consent; fatigue

Communication is a complex process that can be described from different theoretical perspectives. For instance, communication can be described as a process of exchanging or transmitting ideas, attitudes, or beliefs between individuals or groups (National Library of Medicine, 2006), or as a mutual creation of meaning (Mead, 1934/1972). Impairment of communication is a deficit in one or more elements of communication, that is, speech, language, gestures, syntax, and/or semantics (Simmons-Mackie & Damico, 2003). Communication impairment is common among persons with brain damage caused by injury, hemorrhage, or increased intracranial pressure and in degenerative neurological diseases such as multiple sclerosis (MS), amyotrophic lateral sclerosis (ALS), Parkinson’s disease, and dementia. Brain or neurological disease state or injury-induced communication impairment can result in dysphasia, dysarthria, voice disorders, word-finding difficulties, and problems in responding to or comprehending auditory information (Yorkston, Klasner, & Swanson, 2001). Studies have shown that 20% or more of people who have had a stroke or have MS experience speech problems (Beukelman, Kraft, & Freal, 1985; Subcommittee on Brain and Behavioral Sciences, 1991). These disorders might involve cognitive impairments that can negatively affect the ability to communicate because they alter perception, learning, memory, problem solving, and/or speech (McDougall, 2000). Patients on ventilator support and those who are depressed also constitute

Authors’ Note: The research was funded by the County Council of Örebro, Sweden, and the Manitoba Public Insurance Corporation, Canada.
large and vulnerable populations that experience communication problems (Moyle, 2002).

Considering the above-mentioned barriers, it is obvious that obtaining the perspective of individuals living with these impairments would be challenging. In qualitative studies, interview is the most frequently used method for data collection. In this article, our use of the term interview is based on the assumption that an interview is a form of discourse characterized by three components. First, the interview is a speech event. Second, it is constructed by interviewer and informant jointly. Third, the interview is constructed based on the meaning of questions and answers grounded in the actual context (Mishler, 1986).

Researchers often judge people with communication impairments to be impossible to interview and, therefore, most often choose to interview only participants who are articulate, reflective, and expressive in their communication (Paterson, Thorne, Canam, & Jillings, 2001), thereby excluding many individuals with chronic illnesses such as acquired brain damage. In a metasynthesis of 293 qualitative research reports regarding chronic illness, Paterson and colleagues found that only two studies involved informants with impaired verbal communication. Many researchers in the studies they reviewed chose instead to interview the caregivers despite the acknowledgment that caregivers often maintain a different perspective from that of the ill person about what it means to live with the illness or disability (Philpin, Jordan, & Warring, 2005). The exclusion of participants with communication impairments means that “much of the diversity inherent in chronic illness experiences might have been rendered invisible within our research literature” (Thorne, 2002, p. 444).

Qualitative research that has included participants with communication impairments is extremely limited because of the methodological challenges involved. Furthermore, most published reports are not particularly revealing as to how the researchers negotiated the challenge of interviewing participants with communication impairments. A review of current texts regarding qualitative research indicated that most do not identify the methodological issues related to sampling, obtaining informed consent, and fatigue in the participant and researcher. In this article, we will extend previous discussions by identifying methodological issues that to our knowledge have remained largely unaddressed in the relevant literature.

### The Research

As the basis of this discussion, we use our experience in two qualitative research studies in which we interviewed survivors of stroke and traumatic brain injury (TBI). The communication impairments shared by some of the participants in both programs of research included expressive and/or receptive aphasia, paralysis leading to altered nonverbal communication, memory loss causing difficulties with recall, and dysarthria causing a muffled, slurred, or weak speech.

Paterson led a qualitative research study to investigate the experience of survivors of TBI and their significant others in obtaining rehabilitative health care services related to third-party insurance coverage for these services (Paterson, Kieloch, & Gmiterek, 2001; Paterson & Scott-Findlay, 2002). Scott-Findlay was the primary interviewer in this study. The research had an interpretive descriptive design (Thorne, Reimer-Kirkam, & Macdonald-Emes, 1997) and entailed two in-depth interviews per informant. Five survivors of TBI with significant communication impairments participated in the study. A detailed description of the research design for this study is located elsewhere (Paterson, Thorne, et al., 2001).

Carlsson and colleagues (2004) conducted an interpretive descriptive (Kvale, 1996) study on the experiences of living with eating difficulties as part of a larger research project on various aspects of care for...
persons with eating difficulties related to stroke. Three informants experiencing extensive speech problems in addition to their eating difficulties were included. Two interviews, combined with participant observation of a meal, were performed with each informant 1½ to 2 years after their discharge from hospital. Descriptions of the design and participants are presented elsewhere (Carlsson et al., 2004).

Methodological Issues

In the following section, we will focus on the methodological issues that we encountered that extend beyond those previously discussed in the literature regarding the integrity and rigor of the interviews. These issues are (a) sampling, (b) obtaining informed consent, and (c) participant and researcher fatigue.

Sampling

The issues related to sampling of survivors of both stroke and TBI with communication impairments are largely neglected within the relevant literature, and reflections on the implications of inclusion and exclusion criteria used are rare (e.g., Burton, 2000; McColl et al., 2000). A few researchers have noted that certain kinds of brain injuries might lead to difficulties in expressing feelings or experiences (e.g., Nilsson, Jansson, & Norberg, 1997) and comprehension problems (e.g., I. Hamilton, 2000), but the majority of researchers in this area have simply sampled on the basis of a general diagnosis, such as stroke, or with inclusion/exclusion criteria based on the person’s communicative ability. A unique British research project on experiences of aphasia, in which the researchers deliberately selected participants with mild-to-moderate and severe aphasia (Parr, 2001), is a notable exception. These researchers excluded persons who (a) had become aphasic from causes other than cerebrovascular accidents, (b) showed signs of progressive cognitive decline or impairment, (c) were not English speaking, (d) had been aphasic for less than 5 years, and (e) had a marked hearing impairment. The lack of strategies for data collection from the large proportion of persons living with communication problems in addition to chronic illness restrains qualitative researchers from providing a complete picture of the illness experiences, thereby making these experiences invisible in the literature.

We found few studies involving people with communication impairments in which the researchers had assessed potential participants’ communicative or cognitive ability in the recruitment of participants (e.g., Perry & McLaren, 2003). The purpose of the assessment in those studies, however, seemed to be to assure that it would be feasible to achieve valid and rich narratives and not specifically to obtain informed consent.

Assessing an individual’s cognitive capacity in the process of obtaining volunteers for a research study is often a delicate matter. Jimison and colleagues (Jimison, Sher, Appleyard, & LeVernois, 1998) reported that such an assessment might cause anxiety in patients with communication impairments. In a study on the views of persons with learning disabilities on health care, Young and Chesson (2006) discovered that some participants perceived the vocabulary test preceding the interview as a test and extended that view to the interview; that is, they regarded the interview as a test rather than as a genuine opportunity to express experiences and opinions. Such perceptions might impede the ability of the interview to produce valid data.

In a study conducted by Carlsson and colleagues (2004), a two-step process for sampling participants was used. First, staff at a hospital day care clinic identified persons with eating difficulties that they had judged as being able to participate in an interview. This first step entailed a risk that persons with communication impairments would not even be considered for the study. Second, the interviewer met with the potential participants to inform them about the research study and to assess the comprehensibility of their speech. This assessment was based on an experienced nurse’s ability to comprehend impaired speech. No assessment of cognitive capability was made. The researchers developed this sampling strategy because all eligible participants with eating difficulties had speech problems, an impediment that was not foreseen in the original design of the research (Carlsson et al., 2004). Perry and McLaren (2003) assessed potential participants’ communicative and cognitive abilities but did not describe how they used these assessments in the sampling process.

A commonly used strategy in sampling people with communication impairments is the use of proxies, people close to the participant who are expected to be able to represent the impaired person’s experience accurately. For example, Perry and McLaren (2003) included proxies in their study of stroke survivors with eating difficulties “to maximize representation of more-disabled and communication-impaired survivors as their experiences have been particularly poorly researched” (p. 188).
The involvement of proxies in sampling procedures has implications for research involving people with communication impairments. Proxies may have personal views of the value of the research and who can or should participate in it (Lewis & Porter, 2004). In the study by Paterson and Scott-Findlay (2002), a nurse on a rehabilitation hospital unit contacted former patients that she had assessed as being able to participate in a research interview. It is possible that this nurse used criteria beyond clinical signs of cognitive ability to make such a judgment. For example, if her last interaction with the patient had been one in which the patient had been sleepy, the nurse might have determined that he or she would be an unlikely candidate to be interviewed on the basis of his or her slow responses and inattention.

Likewise, family members can function as gatekeepers in research. One family member of a person with TBI in Paterson’s research indicated that she, not her significant other, would be interviewed because “he is too stressed right now with everything that is going on.” Later, the injured person contacted the recruitment nurse and asked why he had been overlooked for the interview. In contrast, the day care clinic staff in the study by Carlsson and colleagues (2004) might have been lenient in their determination of who was eligible to participate in the study because they were skilled practitioners who helped stroke survivors to communicate. They knew the patients’ communication patterns well and were generally able to communicate with them without difficulty; hence, they were unlikely to view the patients’ communication impairments as prohibitive for inclusion in interviews.

Informed Consent

Concerns have been raised about the ability of people with communication impairments to recognize and understand the terms of informed consent. For example, Philpin and colleagues (2005) have suggested that communication difficulties might result in a failure to interpret correctly written or verbal explanations in an informed consent procedure. In addition, people with communication impairments who experience recall problems might sign a consent form and then later forget what they signed or even that they had signed it. Paterson and Scott-Findlay (2002) experienced such an occasion when a participant signed a consent form before the initial interview but, at the time of the second interview, asked if the interviewer was from the government, inquiring about her needs for home care support. Consequently, researchers cannot assume that every person understands the content of the consent and truly gives informed consent in the research and that the participant’s informed consent is long standing throughout the research.

Among medical researchers, there is an active discussion about these matters. In a recent review focusing on the process of communication and informed consent, Albrecht, Franks, and Ruckdeschel (2005) determined that nearly all authors in six studies on informed consent regarding cancer treatment agreed that personal interaction between health care providers and patients is critical to maintaining the integrity and ethical standards necessary to achieve informed consent. Efforts involving the use of multimedia and enhanced consent forms have had only limited success, as reported in a systematic review on interventions to improve research participants’ understanding of information disclosed in the informed consent process (Flory & Emanuel, 2004). Flory and Emanuel recommend that having a member of the study team or a neutral educator spend time discussing the information with participants as the most effective way of improving the participants’ understanding of what is entailed in an informed consent. Various assessment tools have also been used to judge a person’s ability to give informed consent. A process of screening for cognitive impairment and assessing decisional capacity has been described by several authors (e.g., Alzheimer’s Association, 2004; Arscott, Dagnan, & Kroese, 1999; Grisso & Appelbaum, 1995; Palmer et al., 2005); however, we have found no qualitative study in which the researchers explicitly described using such a process.

Interviewing people with communication impairments might cause research participants to experience distress, as they are required to recall painful or stressful occurrences in their illness or disability experience (Philpin et al., 2005). Consent forms for research studies of this nature should include a statement that referral is available for postinterview counseling if the participant requests it. Our experience has been similar to that of Philpin and colleagues, however, in that none of our participants requested this support. This was initially somewhat surprising, as several became extremely distressed during the interview. An interview in a study of the experience of stroke (Carlsson et al., 2004) had to be interrupted because the participant was displaying nonverbal and verbal signs of distress. During debriefing, however, the informant declined counseling and expressed relief that he had had the opportunity to talk about his experience during the interview. On reflection, we recognize that the fact that
no participant requested counseling is hardly surprising as the participants were already entangled in a myriad of health care services, and many indicated that they were tired of meeting and negotiating with new service providers. In addition, people with communication impairments might be reluctant to initiate relationships with practitioners who are strangers who might not know how to interpret their statements.

Responding in an interview might tax the cognitive and linguistic abilities of someone who has communication impairment (Dockrell, 2004). Questioning places considerable demands on a person’s ability to comprehend language and to formulate a response, particularly if the researcher is asking that the person recall painful or negative occurrences (Bloch & Singh, 1999) or if the researcher uses complex grammatical structures or requires the individual to make sophisticated judgments about the phenomenon under study (Dockrell, 2004). This often depletes the energy that the person has available for responding in an in-depth manner, resulting in fatigue and impairing the person’s ability to focus (Montgomery, 2000). This was the experience of Carlsson and colleagues (2004) when interviewing a woman with severe dysarthria. After 15 minutes of the interview, her speech became weaker and more slurred, and she developed a frequent cough. These problems interrupted the flow of the conversation. Although several researchers have identified interviewing techniques that might enhance the participant’s focus during an interview, such as wording questions so as to prompt simple responses (Philpin et al., 2005), there is little mention in the relevant literature around informed consent procedures that participants should be made aware of fatigue as a potential outcome of participating in a research study.

The consent forms that we used indicated that there was no risk to the participants’ physical health in participating in the research; yet it was our experience that many participants experienced intense fatigue during and following the interview. A woman in Paterson’s and Scott-Findlay’s (2002) study fell asleep during the interview and later said, “If I have to concentrate really hard for longer than 15-20 minutes, I am wiped out for the rest of the day.” The consent form she had signed included instruction about how to mitigate participants’ fatigue and impairing the person’s ability to focus (Carlsson et al., 2004; Montgomery, 2000). This was the experience of Carlson and colleagues (2004) when interviewing a woman with severe dysarthria. After 15 minutes of the interview, her speech became weaker and more slurred, and she developed a frequent cough. These problems interrupted the flow of the conversation. Although several researchers have identified interviewing techniques that might enhance the participant’s focus during an interview, such as wording questions so as to prompt simple responses (Philpin et al., 2005), there is little mention in the relevant literature around informed consent procedures that participants should be made aware of fatigue as a potential outcome of participating in a research study.

As reported above, the interview might be a source of considerable angst for participants with communication impairments if they believe that the interview is an assessment tool of their ability to communicate rather than a genuine opportunity to provide their perspectives on the phenomenon under study (Jimison et al., 1998; Young & Chesson, 2006). Such perceptions might impede their ability to fully engage in the interview. Consequently, the description of the study in the informed consent form should clearly state that the interview is not an assessment of the person’s communication ability.

Fatigue of Participant and Researcher

The fatigue that results for many people with communication impairment in interviews can cause the person to misinterpret the researcher’s questions (Camp, Finlay, & Lyons, 2002) and to provide responses that are incomplete and reduced in linguistic complexity or block the flow of their narrative responses (Bloch & Singh, 1999; Johnson, Miller, Curtiss, & Tallal, 1993; Moyle, 2002). This requires that the researcher be particularly attentive to fragmentation, contradictions, or inaccuracies in the person’s statements and use a variety of strategies to assist him or her in focusing on the phenomenon under study. Several authors have discussed strategies for interviewing people who have difficulty speaking or focusing on the topic of the interview, including (a) using interviewers experienced in communicating with persons who have impaired speech; (b) listening carefully, encouraging, and prompting informants during the interview; (c) writing verbatim instead of recording the informant’s speech when it is very unclear; with frequent pauses and few words; (d) offering the informants a list of the broad areas of inquiry in advance; (e) accepting written answers; and (f) using circumstantial field notes (Carlsson et al., 2004; Philpin et al., 2005). However, we could locate no text that included instruction about how to mitigate participants’ fatigue and the resultant lack of focus when the interview is taxing.

The informants’ decreased ability to focus was a particular challenge for Paterson and Scott-Findlay (2002) in their study involving survivors of TBI. Interview responses were often disjointed, fragmented, and peripheral to the question that had been asked. When prompted by the interviewer, participants often admitted they had forgotten the interview question and needed it repeated, as can be seen in this example:

**Interviewer:** So, what was it like the first day you were alone at home with your children?

**Participant:** It was—I thought—Well, my husband, he went to work—It was after my last time in hospital. I had trouble with my doctor. Did I tell you that?
**Interviewer:** Was the trouble with your doctor related to being home alone with your children?
**Participant:** No. Why did you say that? It was about my applying for disability.

**Interviewer:** Well, I had asked you about how you felt when you were alone for the first time with your children.
**Participant:** Oh, yes. I forgot. I can’t seem to focus today.

Similarly, Carlsson and colleagues (2004) experienced challenges in the interview situation related to the decreased ability of the respondents to focus, increasing slur, weakening voice, and increasing monosyllabic speech as the interview continued. This is exemplified here in an excerpt of their interview with a participant who had experienced a stroke:

**Interviewer:** Did it take long before you could control the bolus in your mouth?
**Participant:** Yea—
**Interviewer:** Did you have that tube inserted to your stomach at once?
**Participant:** No—I—my weight, it was when I had such low weight. (Slurred voice)
**Interviewer:** So you lost so much weight? And then the doctors talked to you about having a PEG-tube [percutaneous endoscopic gastrostomy tube]?
**Participant:** It was her—the speech pathologist—(Voice almost inaudible)
**Interviewer:** It was her who arranged so you got a PEG?
**Participant:** Yea—(stifles a yawn, looks tired)

The research teams led by Carlsson and Paterson found that the intensity of such an interview caused the researchers to become fatigued in a shorter time than they would normally. We can recall needing a nap after particularly arduous interviews. When we as researchers became tired as we struggle to understand and focus in the interview, we were less adept at picking up the clues that participants presented us, and we often forgot to return to earlier comments that required further explication. For example, in the following quote from Paterson’s research, the interviewer failed to ask the participant to clarify what she meant or to give examples.

**Participant:** So it was the thing, the main thing, why I was angry. I know that I can get emotional. My husband is always telling me that. Since my injury, you can’t trust much of what I say.
**Interviewer:** So what happened to your physiotherapy appointments after you came home?

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**Strategies to Address Methodological Issues**

Although we were able to generate solutions and ways of addressing some of the methodological challenges we encountered in our research, we offer additional insights from other disciplines such as communication studies and aphasiology.

We have criticized sampling procedures in qualitative interview studies because of the researchers’ unreflecting exclusion of persons with communication problems. Drawing on insights derived from research by Parr and colleagues (1997) and our own experience, it is possible to design studies in which persons with impaired communication can be active participants. What is crucial is to recognize that these persons need to be included and that their inclusion will contribute a breadth and depth to the data that would not be achieved by those who are marginal to the experience of disease or disability. People with communication impairments can advise qualitative researchers about the design of the research and assist in developing relevant sampling and interviewing procedures. Such involvement of the target population is described by Parr and colleagues in their research.

Strategies to address the ethical issues related to obtaining informed consent in research involving people with communication impairments have been discussed to a limited extent by Carlsson and colleagues (2004) and Philpin et al. (2005). For example, these authors indicate the need to ensure that the person with communication impairment understand what is written in the informed consent form. There are, however, additional strategies, such as using augmentative and alternative communication (AAC) (Beukelman & Mirenda, 1998), that these researchers have not proposed. AAC refers to ways, other than speech, that are used to communicate between persons, such as facial expressions, gestures, writing, and a variety of AAC devices ranging from simple picture boards to complicated digitalized speech devices. Jimison et al. (1998) developed and used such a device in a study on patients with potential cognitive impairment. Their multimedia tool consisted of several information modules in a computer with touch screen capability, using video, written information, and pictures. One module was a cognitive self-test; another provided either signature or voice approval to take part in the study.

One example of a low-tech AAC device to obtain informed consent is the Talking Mat, a visual framework consisting of picture symbols detailing the topics...
to be explored or addressed, options for each topic, and a visual scale to allow the participant to indicate his or her desires and opinions about each option that is presented (Murphy, 2000; Murphy, Tester, Hubbard, Downs, & MacDonald, 2005). This reduces the memory and linguistic demands for people with communication impairments, as illustrations are likely to be processed more easily than words. The pictures are attached by Velcro to a mat and can be moved as the participant formulates responses, which allows for both verbal and nonverbal responses. For example, the participant can indicate his or her selection of an option by mere hand movements or eye pointing. It also allows for participants who are slower than the norm to take their time responding to questions or requests (Murphy et al., 2005).

Talking Mats have been used successfully in interviews of people with communication impairments resulting from Alzheimer’s disease, stroke, and learning disability (Killick & Allan, 2001; Murphy, 2000; Murphy et al., 2005); however, we know of no occasions of their use to present informed consent information. If Talking Mats were used in this context, pictures might be used to portray the various components of the consent (e.g., description of study, inclusion and exclusion criteria, assurance of confidentiality, the possibility of foreseeable risks or discomforts), breaking the consent into manageable chunks of information (Grisso & Appelbaum, 1995) contained in supporting symbols (Murphy et al., 2005). Participants could indicate verbally or by nonverbal gestures their willingness to participate in the research and their understanding of what is included in the consent by indicating their selection on a visual scale. The visual scale for willingness to participate, for example, might consist of face symbols on the mat, indicating “yes,” “unsure,” and “no.” To validate participants’ selections, at the end of the session, the interviewer could ask them to confirm their choices. A digital photograph of the completed mat should be filed, and a copy given to the participant, as a record of the consent.

The consent form for research involving people with communication impairments should state clearly that fatigue and/or discomfort are common during such interviews and that for participants to be able to participate fully, they should tell the researcher when they need a break or for the interview to be continued at a later date. Paterson and Scott-Findlay (2002) made the point that researchers should provide time at the completion of the interview to debrief the participant about the interview process. Debriefing could include engaging the participant in conversation about the emotional impact and discussing how the participant might deal with the emotional aftermath of the interview. The consent form should state clearly that debriefing will occur and that the researcher will discuss possible resources and/or strategies for mitigating the emotional impact of recounting painful narratives.

On review of our interview transcripts, we were able to detect that our fatigue had negatively affected our ability to ask salient questions and to encourage participants to reflect, as we became unable to attend acutely to the participant’s responses. The implication of this is that when interviewing participants who have communication impairments, researchers should schedule shorter interviews than are typical. Three 30-minute interviews are likely to be more productive than one 90-minute interview. In addition, researchers should review the tapes or transcriptions of the interview to identify areas that require further clarification or expansion in a later interview.

The following questions, derived from the fields of learning disability and communication, are helpful in promoting reflection about the effect of researcher fatigue on research findings (Lewis & Porter, 2004).

- Are my questions less focused than they were in the first 15 minutes of the interview?
- Have I explored the participant’s perception of the implications of what he or she has said? If not, why not?
- Have I been yawning, fidgeting with my hands or feet, or squirming in my chair?
- Am I being distracted by people or things around us?
- Am I listening attentively to what the participant is saying, picking up contradictions, ambiguities, and statements that require further explanation or clarification?

**Discussion**

People with communication impairments have expressed that they are more or less invisible in society (Newborn, 1998; Parr et al., 1997; Sarno, 1993). In the preceding section, we suggested that the same might be said to be true in qualitative research. All of the participants in the study of the stroke experience conducted by Carlsson et al. (2004) expressed a fear of not being
understood by the interviewer. We believe that if we were to interview qualitative health researchers, we might find that they, too, are concerned that they will not be able to fully understand people with communication impairments and represent them appropriately in research reports. We could locate no research or other literature that specifically discussed how to increase researchers’ skill and confidence in interviewing people with various communication impairments.

Our purpose was to discuss methodological issues in qualitative interviews. However, other research methods might be used to explore experiences of persons with communication problems. Studying experiences of living with eating difficulties after stroke, for example, might benefit from an ethnographic design, or from life history research (Goodson, 2001) using autobiographic texts.

In this article, we have proposed alternative strategies for involving people with communication impairments in qualitative interviews about their experience of living with acquired brain damages. This calls for the development and sharing of creative approaches to ensure their active participation in qualitative research studies. One such example is that of Lemieux and colleagues (2001), who studied aphasia and sexuality using a method called supported conversation for aphasic adults (SCA) (Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001). This method focuses on conversation between the interviewer and the person with a disability. The interviewer must be trained as a conversational partner for persons with aphasia. This method is an example of the need for deeper knowledge in neuropsychology and related fields to be able to adjust data collection methods to the type of communication problems that participants experienced in our research. Although some researchers have proposed the use of pictures and symbols in such research, others have expressed concern that using pictures or symbols might constrain the participant’s responses (Lewis & Porter, 2004). Future researchers should investigate how approaches used in speech therapy and other areas (e.g., learning disability) might be adapted to interviewing of people with communication impairments. It is essential that people with communication impairments be involved in such research to advise researchers about their response to these approaches.

The process of obtaining valid informed consent is a crucial component when planning a qualitative study involving persons with communication impairments. The complexities of providing informed consent to someone with communication impairment might be one reason why this population is often excluded from qualitative studies. In this article, we have discussed the process of achieving informed consent and problems related to informing about the research in relation to cognitive impairment. We have also presented two examples of AAC aids that might facilitate this process. Further research about creative ways to obtain truly informed consent among participants with communication impairments is of great importance.

Drooling, uncontrolled cough attacks, and facial droop are common symptoms and sources of great concern for many persons surviving a stroke (Dikeman & Kazandjian, 1998), and impaired speech has often been seen as implying diminished mental competence (Sarno, 1998). For a person with those problems, being excluded from participation in a research interview could be viewed by them as evidence of their ineptitude and failure. Researchers should be aware of such a possibility when conducting interviews of people with communication impairments. When recruiting participants with communication impairments in qualitative interviews, we have to be aware to avoid inclusion and exclusion criteria and methods that can convey that such participants are not “good enough” for such research. Instead, continued efforts should be directed toward finding methods to facilitate and enable those persons to communicate their experiences within qualitative interviews.

A research interview is often a tiring activity for both the interviewer and the informant. In our experience, it is even more tiring when the informant is a person with communication problems. We have described how we felt exhausted after the interview and how participants showed signs of fatigue or even fell asleep. These experiences and knowledge about effects of fatigue on cognitive function have implications for the planning of the qualitative interview with such a population. We can draw on fields such as learning disabilities and aphasiology to develop interview techniques that acknowledge these effects (Dockrell, 2004; Lewis & Porter, 2004), for example, interviewing more than once and conducting short interviews.

Designing interviews with people who have communication impairments requires that the researcher be sufficiently knowledgeable about the specific nature of the impairments and its effects on the interviewing process. For example, an interview with aphasic persons would have to be different from that with persons with dysarthria or anarthria because of how each condition poses unique challenges in the interview. Knowledge from the fields of learning disabilities and aphasiology...
could be used in this crucial component of research planning and in the development of relevant interview techniques (Dockrell, 2004; Lewis & Porter, 2004). One design for interview studies that has appeared in research reports lately is the use of the Internet (e.g., Adams, Rodham, & Gavin, 2005; Piamjariyakul, Bott, & Taunton, 2006). Online discussion forums have been found to open up discussion of sensitive topics and forms of self-expression that are difficult to capture in face-to-face interactions. Furthermore, the anonymity of the Internet might make it easier to share experiences and express usually private parts of us: a more authentic self than what is possible to expose in real-life encounters (Adams et al., 2005; Bargh, McKenna, & Fitzsimmons, 2002). In the context of communication impairment, people with, for example, speech problems might benefit from such data collection methods; however, verbal dialogue cannot unreflectingly be replaced by Internet interviews, and there is an active discussion going on in health care research on the advantages and disadvantages of using this medium (R. Hamilton & Bowers, 2006; Kralik, Price, Warren, & Koch, 2006).

Conclusion

We have identified a number of practical strategies to enhance the efficacy of the qualitative interview with people who have communication impairments. The primary focus of the article was on strategies to involve the large share of persons with communication problems in addition to acquired brain damages such as stroke and TBI. However, our findings from studies in learning disabilities indicate that our suggestions will be valid in studies specifically focusing on living with communication problems. These include more than one interview and debriefing after each interview. Our most significant message, that the opportunities to voice personal opinions and experiences are valued contributions to research, is echoed by our participants and in the findings of other researchers (e.g., Goldsmith, 1996; Moore & Hollett, 2003). It is important that we discover effective ways to capture their voices in such research.

Knowledge about the experiences of persons living with illness or disability is essential for the development and provision of good nursing care for those large populations, including a large proportion of persons with communication impairments. Three aspects of the qualitative research process involving persons with communication problems that have been poorly developed are sampling, informed consent, and fatigue in the participant and researcher. We have suggested possible strategies and tools, and have stressed important areas for further discussion and research. Persons with communication impairments related to stroke or TBI constitute a large group in need of continuous health care. Findings from studies involving persons with communication impairments can provide important contributions to the development of this area of research (Parr et al., 1997). There is a need for increased awareness of this important area and for the development of researchers’ communication skills and knowledge about neuropsychology to facilitate further exploration of the experiences of these patient groups.

References


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Doktorsavhandling/Doctoral thesis with focus on Nursing.

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Vetenskaplig uppsats för licentiatexamen/Academic essay.

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Doktorsavhandling/Doctoral thesis with focus on Nursing.

Doktorsavhandling/Doctoral thesis with focus on Nursing.

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20. Lidskog, Marie (2008) *Learning with, from and about each other: Inter-professional education on a training ward in municipal care for older persons.*
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Doktorsavhandling/Doctoral thesis with focus on Nursing.