

Quality in the continuum of care for frail older persons - Structure, process and outcome

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ABSTRACT

Frail older persons are often dependent on care and support from several different care providers, including hospital and primary health care as well as municipal health and social care. The increasing complexity of care requires attention to quality issues. The overall aim of this thesis was to explore quality of care for frail older persons in regard to continuum of care. The focus was on organizing integrated care (i.e. structure), older persons' influence on care-planning meetings (i.e. process) as well as the older persons' views of quality of care and life satisfaction (i.e. outcome). Paper I included official reports on ways of organizing integrated care in Sweden during the past decade. Data for Papers II-IV were collected in an interdisciplinary intervention project, including assessment of need for health/social care and rehabilitation at the hospital, interprofessional teamwork, a municipal case manager, the organizing of care-planning meetings in the older persons' homes and support for relatives. The data analyses consisted of a meta-analysis of cases (Paper I), qualitative content analysis of audio-recorded care-planning meetings (Paper II) as well as statistical analyses of frail older persons' views of quality of care (Paper III) and life satisfaction (Paper IV).

The development of organizing integrated care over the past decade included several different strategies, some of them implying a direction towards enhanced integration, but others a direction towards fragmentation of care. Reported goals focused on the care providers' perspective rather than the older persons' perspective. Furthermore, the organizing of care-planning meetings in the older persons' own homes appeared to enable older persons' participation. However, their possibilities to obtain real influence over the way of delivering or organizing home care were restricted by organizational rules, regardless of where the meetings took place.

The intervention had a positive effect on older persons' own evaluations of quality of care. Those who received the intervention rated higher quality on all items of care planning and they also had better knowledge of whom to contact. In addition, the intervention had a positive effect on the older persons' life satisfaction, including satisfaction with functional capacity, psychological health and financial situation. Policymakers, managers and professionals within health and social care are suggested to further promote the establishment of comprehensive continuum of care for frail older persons, in order to enhance quality of care from the older persons' perspective.

Keywords: care planning, collaboration, content analysis, continuum of care, frail older adults, organization, outcome assessment, participation, personal satisfaction, quality of health care, randomized controlled study

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- III Berglund H, Wilhelmson K, Blomberg S, Dunér A, Kjellgren K & Hasson H. Older people's views of quality of care: a randomised controlled study of continuum of care.
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INTRODUCTION

The complexity of health and social care for older persons calls for attention to quality issues, especially regarding the frail older persons who are most in need of care. Frail older persons are often dependent on care and support from several care providers, such as hospital and primary health care as well as municipal health and social care. A well-functioning integration between the different providers is essential in order to satisfy their individual and complex needs. This is also formally addressed in national policies and health- and social-care legislation (Department of Health 2008, SFS 1982:763, 2001:453). Frail older persons living in their own homes are frequently admitted to hospital (Burt & McCaig 2001, Condelius *et al.* 2008), and when they move from hospital to home high-quality co-ordination of care is especially important (Naylor & Keating 2008). Several deficiencies have been identified in the continuum of care, especially during the time directly after hospital discharge. These deficiencies are well documented (Coleman *et al.* 2004, Forster *et al.* 2004, National Board of Health and Welfare 2011c). There is a risk of fragmentation of responsibilities, which may result in quality problems such as duplications, gaps and discontinuity (Axelsson & Bihari Axelsson 2006, Clarfield *et al.* 2001, Glendinning 2003). This fragmentation may in turn lead to concerns for the older persons, especially those of dealing with unmet care needs (Bowles *et al.* 2003, Gurner & Thorslund 2003).

The overall aim of this thesis was to explore quality of care for frail older persons, in regard to continuum of care. The overarching concept is quality of care, including a model of structure-process-outcome (Donabedian 1980, 1988, 2003). Structure is explored regarding ways of organizing integrated care, as found in cases of development work in Sweden and in relation to theoretical underpinnings on integration (Paper I). Processes are analysed as they occur in care-planning meetings, which are important focal points in the continuum of care where professionals and the older persons meet to plan for the next steps of care. The study primarily concerns older persons' influence on these meetings (Paper II). Regarding outcomes, the thesis is limited to covering effects of a continuum of care intervention on older persons' evaluations of quality of care (Paper III) as well as life satisfaction (Paper IV).

Disposition of the thesis: The thesis is divided into two parts. In the first part the background, overall and specific aims, theoretical framework and methodology of the thesis are presented. In this part I also provide a summary of the results in the four papers and a general discussion. The second part of the thesis contains the four original papers.

Before the next section, I will add some clarifying remarks regarding the presentation of previous research. In the background section previous research of interventions focusing on continuum of care for frail older persons is presented. Previous research on integration and integrated care and older persons' influence on care-planning meetings is provided in Papers I and II as well as in the theoretical framework and the discussion sections of the thesis.

BACKGROUND

Development of elderly care in Sweden

In Sweden, care of older persons has changed considerably during the past decades. The Elderly Care Reform (Ädelreformen) was introduced in 1992, and it implied that the responsibility for care services for older persons, including special housing, was moved from the county councils to the municipalities. The reform intended to improve integration of care and promote a more efficient use of resources. Older persons often remained in emergency and geriatric hospital clinics otherwise, even if they did not need further medical care (Government Bill 1990/91:14 1990).

There has been a significant reduction of hospital care for older persons since the introduction of the Elderly Care Reform, as regards number of beds and lengths of stay in geriatric care. Seventy-five per cent of bed capacity in geriatric care was closed between 1992 and 2008. The average length of stay decreased from 21.5 days in 1993 to 12 days in 2008 (for those 80 years and older) (National Board of Health and Welfare 2009a). Therefore, older persons often leave hospital now with remaining care needs (Szebehely & Trydegård 2012). Additionally, it has become more common for older persons to live in their own homes instead of in special housing (National Board of Health and Welfare 2012). The amount of older persons (≥ 65 years) living in special housing decreased by about 20,000 persons between 2002 and 2009 (National Board of Health and Welfare 2011a). These circumstances, in combination with an ageing population in Sweden, have increased the challenges for primary health care and municipal health and social care.

However, tighter budgets in the municipalities have resulted in raised thresholds within elderly care (Szebehely & Trydegård 2012). The proportion of older persons (65 years and older) with less care needs receiving publicly funded home help services decreased significantly between 1988-89 and 2004-05 (from 44% to 34%). Home help services as well as special housing are increasingly restricted to those with the greatest needs (Szebehely & Trydegård 2012, Trydegård 2003). Since the reduction of hospital care and special housing, more persons with increasingly advanced illnesses receive home nursing care in their own homes as compared to before, and more qualified health care tasks are performed (National Board of Health and Welfare 2008a).

In addition, there is an increasing private sector involvement in health and social care in Sweden, which focuses on competition between different care providers (Ahgren & Axelsson 2011, Erlandsson *et al.* 2013, Szebehely & Trydegård 2012). The proportion of home help service carried out by private providers has increased in previous years, and in 2012 constituted about 23% of home help service hours in the whole country. The proportion differs greatly across the country, with the highest proportion in the Stockholm region (National Board of Health and Welfare 2013a). Several initiatives intend to increase older persons' influence and choice within health and social care, such as the intensified emphasis on user influence in elderly care (Brukarinflytande inom äldreomsorgen) and the introduction of a freedom of choice system (Valfrihets-

system) (Ministry of Health and Social Affairs 2008, National Board of Health and Welfare 2008b, SFS 2008:962).

In Sweden, formal care is evaluated and reported in open/regional comparisons. Different quality indicators are reported, such as continuity, older persons' participation and information, within elderly care (Swedish Association of Local Authorities and Regions & National Board of Health and Welfare 2013a). Also reported are medical outcomes, availability and patient experiences, especially in hospital care (Swedish Association of Local Authorities and Regions & National Board of Health and Welfare 2013b). The purpose of these comparisons is to make publicly financed care systems more transparent for the public, to control outcomes and to give policymakers a basis for monitoring and improving quality.

Additionally, National Healthcare Quality Registries have made it possible to follow up and improve quality of care. These registries include diagnoses, treatments and outcomes (Andersson 2013, Sousa *et al.* 2006, Swedish Association of Local Authorities and Regions 2010). Today their application has become wider, as increasingly more registries have moved beyond medical data to include patient-reported outcome measures, such as perceptions of quality of care and quality of life (Swedish Association of Local Authorities and Regions 2010).

It is important to note that the development of health and social care for older persons has resulted in increased involvement from their relatives. It has been shown that about 58% of older persons (≥ 65 years) who need assistance with one or more activities of daily living receive help exclusively from family or other informal carers. In addition, 23% receive help from both formal and informal carers (Sundström 2009). However, this thesis focuses only on formal care for older persons, and specifically on the quality of this care.

Frail older persons

Frailty is a term that is used to identify vulnerable older persons. The term is closely related to multiple chronic conditions and disability. It can be defined as increased vulnerability to stressors due to decreased physiologic reserves (Fried *et al.* 2004). Conditions such as weakness, exhaustion, weight loss, low physical activity and slow gait are included in the frailty syndrome (Fried *et al.* 2001). There is also consensus about comprising other conditions that might appear, such as impaired balance and mobility as well as decreases in cognitive function (Fried *et al.* 2004). Frailty is strongly associated with chronic diseases such as cardiovascular diseases and diabetes, and there is a greater likelihood of frailty when the older person has two or more diseases (Fried *et al.* 2001).

In line with other researchers, I have adapted a more comprehensive approach to frailty, including physical, psychological and social functioning (Gobbens *et al.* 2010, Nourhashémi *et al.* 2001). Gobbens *et al.* (2010) emphasize the risk that a focus on just physical functioning jeopardizes attention to the older person as a whole. This could lead to fragmentation of care and a reduction in quality of care for frail older

persons. Furthermore, frailty is associated with low levels of well-being and life satisfaction (Andrew *et al.* 2012, Strawbridge *et al.* 1998). It is also connected with poorer health and lower education/income and it has been discovered that the likelihood of being frail is higher in women (Fried *et al.* 2001).

Frail older persons are at high risk of adverse health outcomes such as falls, disability, hospitalization and death (Fried *et al.* 2001), which makes it clear that actions need to be taken to prevent these risks. There is a need for comprehensive interventions, comprising screening of those at risk of being frail and geriatric assessment including accurate diagnosis of age-related diseases, health and social situations (Vellas *et al.* 2012).

Care for frail older persons

The responsibility of a well-functioning continuum of care is divided between the county councils and the municipalities. The county councils are obligated to provide health care to the whole population. Hospital care should be available when required. The responsibility of primary health care is to provide basic medical and nursing care, preventive care and rehabilitation for the population, including frail older persons. It is restricted to care that does not require the hospitals' special resources (SFS 1982:763). In a review by the National Board of Health and Welfare (2011b) it was shown that care for frail older persons includes in particular medical care at primary health care centres, special housing and home nursing care as well as home visits by health care professionals and pharmaceutical reviews. However, there is a lack of systems for identifying frail older persons.

In Sweden, home nursing care can be provided by the county council or the municipality. The municipalities have a possibility to take over the responsibility of home nursing care given in the person's own home, if they can reach an agreement with the county council and the government (Government Bill 1990/91:14 1990). In 2012 about 60% of the municipalities in Sweden were responsible for home nursing care (National Board of Health and Welfare 2013b). The government's intention is to promote further transfer of home nursing care from the county councils to the municipalities. Several municipalities are investigating their potential of taking over that responsibility, or plan to take over between 2013 and 2015 (Ministry of Health and Social Affairs 2011). The organization and content of home nursing care differs quite extensively across the country. It has been shown that there are local differences regarding access to examination and treatment in older persons' own homes, and care needs are not always met (National Board of Health and Welfare 2008a).

Home help service and other support for older persons is the responsibility of the municipalities, and they are regulated by the Social Services Act (SFS 2001:453). It includes a right to good quality support if needs cannot be met in another way, but there are no details or specifications. The municipalities have autonomy regarding provision of help, and needs assessment is carried out by a social worker. Home help service includes help with household tasks such as cleaning, shopping, laundry and delivery of food as well as personal care such as getting dressed and bathing. The amount of home help services varies from help once a month to several visits every

day. Emotional and social support may also be provided (Szebehely & Trydegård 2012). In this thesis home care and home care services are used as inclusive terms for home help service and home nursing care.

Continuum of care for frail older persons

Due to changes described above in care of older persons the amount of providers involved in the care has increased, which has necessitated improvements in communication and co-ordination. Today's short hospital stays put an increased emphasis on primary health care and municipal health and social care for frail older persons, and their transitions between different care settings. At some point, as a result of the changes in the conditions for health and social care, the concept of "*vårdkedja*" (continuum of care) emerged, to describe the need for a comprehensive system of care for older persons and the importance of communication and co-ordination between providers. In the literature several terms with similar meanings can be seen, such as chain of care, therapy line, continuum of care and integrated care. The term chain of care is a direct translation of the Swedish word "*vårdkedja*". It might symbolize care activities as links in a chain. Chain of care can be defined as co-ordinated activities linked together, including all care provided for a specific group of patients (Ahlgren & Axelsson 2007). "*Vårdkedja*" may also be translated as therapy line. Lindberg & Trägårdh (2001) suggested that chain of care and therapy line can be seen as ideas, based on organizing the flow within health care.

In a concept development study, continuum of care was defined as a series of initiating, continuing and concluding care events (McBryde-Foster & Allen 2005). This is the result when a patient (in this case an older person) seeks providers in one or more environments within the health care system. Four main characteristics were found in the continuum of care: persons, environment, events and time. Keywords related to persons were first of all the older person and the provider. Environmental words included management and integration. Events could be of three different kinds: event antecedents (i.e. older persons' needs), events during the experience of care (i.e. care planning, discharge, transition) and events that are consequences or outcomes of care (i.e. health, quality of life). Finally, words describing the attribute of time included continuum and continuity. The older person progresses through the environments over time, experiencing changing care events, relationships and communications (McBryde-Foster & Allen 2005).

Integrated care has been described as an important framework for developing better and more cost-effective health systems. It can be seen as the result of efforts to promote integration for the benefit of special patient groups (Kodner & Spreeuwenberg 2002). The concept of integrated care is used in one of the studies in this thesis (Paper I), and its definition and meaning is further elaborated upon in the theoretical framework (page 20).

Health care systems are judged to be the most complex entities known to society (Kodner & Spreeuwenberg 2002). Considering this, it is also obvious that it is very complicated to describe concepts involved in this system, like the Swedish "*vårdkedja*". All of the English terms, as described above, seem to consist of some attributes

that concern the Swedish concept. Continuum of care has been described in terms of care events and processes, while integrated care has been described as the result of efforts to promote integration. It seems that time continuum and a person's transition between different environments are typical attributes for the meaning of continuum of care. The concept focuses on time and ongoing processes, and is not necessarily a result in itself. But the term seems to comprise many processes on different levels where results can be included. McBryde-Foster & Allen (2005) suggested that events could include consequences or outcomes of care, such as changes in health. I consider continuum of care to be a series of linked and integrated care events that occur when frail older persons need the different care providers and environments. The continuum of care concept is used in the intervention project (Wilhelmson *et al.* 2011), which is a basis for Papers II, III and IV in this thesis.

The attributes for the continuum of care for frail older persons can be simplified and illustrated as in Figure 1.

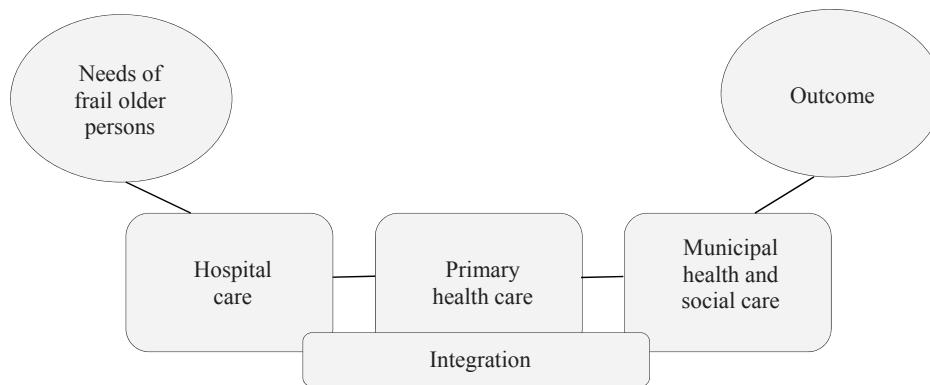


Figure 1. Illustration of attributes for the continuum of care for frail older persons (modified from McBryde-Foster & Allen 2005, page 630).

A movement towards more individualized health and social care is of essential importance in the continuum of care for frail older persons. These persons are vulnerable and the professionals must pay particular attention to their personal abilities and needs. This is a challenge for all care providers involved in the continuum of care for frail older persons.

Previous interventions with focus on continuum of care

Previous interventions with focus on continuum of care have shown positive effects on older persons' own evaluations of quality of care. The inclusion of a coordinator/case manager has been shown to be of special importance to older persons' satisfaction with delivery of care (Hébert *et al.* 2010, Stewart *et al.* 2013). In addition, individually tailored care plans, mostly performed by a coordinator/case manager, have

shown to bring greater satisfaction with care planning (Preen *et al.* 2005, Shepperd *et al.* 2010, Shepperd *et al.* 2013) and higher participation among the older persons as compared to control groups (Preen *et al.* 2005). In a meta-analysis Preyde *et al.* (2009) concluded that a coordinator/case manager who conducted the care planning and interprofessional teamwork had a positive effect on older persons' satisfaction. Additionally, geriatric assessment in combination with a case manager showed better knowledge among the older persons of whom to contact with questions (Dedhia *et al.* 2009).

Studies of effects of continuum of care interventions on older persons' life satisfaction seem to be lacking. However, in a systematic review of studies including care planning and co-ordination by a case manager consistent evidence could be shown regarding improvements on older persons' subjective well-being (You *et al.* 2012). Positive effects on quality of life were shown in studies comprising individualized, comprehensive care planning and post-discharge home visits (Lin *et al.* 2009). In addition, augmented care planning with a coordinator/case manager and interprofessional teamwork showed beneficial effects on quality of life (Preyde *et al.* 2009). However, other studies including augmented care planning and co-ordination showed no effect on quality of life (Weinberger *et al.* 1996) or, respectively, better quality of life in the control group (Sulch *et al.* 2000).

Rationale of the thesis

In order to obtain integration in the continuum of care, organizational issues need to be addressed. Several strategies at different levels are known, but how these are elaborated upon in practice is not well explored. Furthermore, it is especially important to focus on the situations where professionals and the older persons interact with each other. Within these interactions the professionals are supposed to create a trustful relation, in order to establish good conditions enabling the older person to tell what he/she wants. However, if the situations are strictly regulated by rules, it may be more difficult to establish these conditions (Efrainsson 2007). Therefore the performance of care-planning meetings and the older persons' influence on these meetings requires special attention by policymakers, managers and professionals. Effects of continuum of care interventions have been studied previously, as described above (relevant papers are also discussed in Papers III and IV and in the discussion section), but there is a need of further studies in this area (Eklund & Wilhelmson 2009).

AIM

The overall aim of the thesis was to explore quality of care for frail older persons, in regard to continuum of care. The focus was on organizing integrated care (structure), older persons' influence on care-planning meetings (process) as well as their views of quality of care and life satisfaction (outcome).

Specific aims

- to describe and analyse ways of organizing integrated care for older persons in Sweden during the past decade
- to describe and analyse older people's influence on care-planning meetings at home and in hospital
- to analyse frail older people's views of quality of care when receiving a comprehensive continuum of care intervention, compared to those of people receiving the usual care (control group)
- to analyse effects of a comprehensive continuum of care (intervention group) on frail older persons' life satisfaction as compared to those receiving usual care (control group)

THEORETICAL FRAMEWORK

A model of quality of care is presented here, as well as theoretical underpinnings for integrated care, care planning, influence and life satisfaction.

Quality of care

An overarching concept in this thesis concerns quality of care, as it appears in the continuum of care. Quality is first of all a property that care can have in varying degrees. Often it is described normatively, based on what is agreed to be good or acceptable (Donabedian 1980). The National Board of Health and Welfare defined quality as being “that an activity fulfils the requirements and goal that are applicable to that activity according to the laws and regulations for health and medical care, social services and support and aid to certain persons with functional disabilities” (SOSFS 2011:9 2011, translated by editor). Furthermore, it can be described as comprising two basic inter-related domains: technical and interpersonal care. Technical care is the application of science to the management of a person’s health problems and interpersonal care concerns the relationship between the person (in this case the older person) and the professionals (Donabedian 1980).

Structure, process and outcome

Donabedian (1980, 1988, 2003) describes quality of care as a model, comprising three different approaches: structure, process and outcome. This model has been widely used, especially regarding evaluations and improvements of quality of care. Initially the model was developed in the context of medical care, but it has also been shown to be relevant for nursing (Dubois *et al.* 2013, Gardner *et al.* 2014, Idvall 2013, Kobayashi *et al.* 2011) and other areas of health care (Donabedian 2003). In Sweden the model is used in evaluations reported in national comparisons and registries (Erlandsson *et al.* 2013, Idvall 2013).

Structure refers to the conditions under which care is provided (Campbell *et al.* 2000, Donabedian 2003). Such conditions include material resources (e.g. facilities), human resources (e.g. number and qualification of professionals) as well as organizational characteristics (e.g. how delivery of care is organized) at different levels (Donabedian 1980, 2003). The mix of professional expertises and the organization in interprofessional teams are examples of these conditions (Attree 1996, Gardner *et al.* 2014). Process, in turn, involves activities regarding both technical and interpersonal care (Campbell *et al.* 2000, Donabedian 1980, 2003). Assessment, care planning, actual delivery of care, users’ participation as well as commitment to their individual needs are examples of such activities (Attree 1993, 1996, Dubois *et al.* 2013). Outcome refers to consequences of care. At the individual level, outcomes comprise the effect of care on health, such as functional capacity and symptom relief as well as users’ evaluations, for example satisfaction with care (Campbell *et al.* 2000, Donabedian 2003). Changes in users’ knowledge, psychological health (Donabedian 2003) and quality of life (Attree 1996, Donabedian 2003, Dubois *et al.* 2013) may also constitute consequences of care.

The relationship between structure, process and outcome seem to be complex. To simplify the relationship, structure influences process and process influences outcome (Donabedian 1980, 2003). But structure may also influence the outcome, either indirectly or directly (Burns & Grove 2001, Campbell *et al.* 2000). It is not always clear where structure ends and process begins or where process ends and outcome begins (Donabedian 2003). However, in a recent study by Gardner *et al.* (2014) it was shown that the model by Donabedian is a valuable approach for exploring the interdependence between structure, process and outcome.

Older persons' perspective of quality of care

Quality of care can be considered from different perspectives, such as those of the provider and the user (the user will henceforth be called the older person) (Attree 1996, Donabedian 1980). The term provider can cover a broad range from an individual professional to several professionals, teams and care systems (Burns & Grove 2001, Donabedian 1980).

Campbell *et al.* (2000) suggest that quality of care has the most meaning when applied at the individual level. Several researchers focus on the needs of the older persons in their explorations of quality of care (Campbell *et al.* 2000, Dubois *et al.* 2013, Sixma *et al.* 1998). This view is referred to as the characteristics of care, which bear on its ability to satisfy stated or implied needs of the older person (Sixma *et al.* 1998). The following definition of quality of care was suggested by Campbell *et al.* (2000): “whether individuals can access the health structures and processes of care which they need and whether the care received is effective” (page 1614). Access includes the extent to which the care system provides structures and processes that meet the needs of older persons. Effective care is the extent to which care delivers an outcome in a desired process, in response to needs. Processes and outcomes are context-specific for each person because quality of care requires the consideration of individual circumstances. Effective care, therefore, requires an evaluation of the person's own experiences (Campbell *et al.* 2000).

In a study by McCormack *et al.* (2008) older persons (≥ 65 years) were interviewed about quality of care. Continuity of care, including long-term continuity after discharge from hospital, was a key issue for the older persons. Many of the older persons felt disempowered by the system of care delivery, as they were not included in decision-making about their own care. This implies that process (participation and influence), but also structure (organizing continuity) have essential impacts on older persons' assessment of quality of care.

Older persons' perspective of quality of care is deeply connected with their satisfaction with care. Satisfaction with care can be seen as one possible operationalization of the quality of care concept (Sixma *et al.* 1998). In a concept analysis by Wagner & Bear (2009) satisfaction with care was considered to be one of the key outcomes of care. Some researchers define satisfaction in terms of personal evaluation based on personal preferences and expectations (Ware & Hays 1988). Others question the relevance of involving expectations and stress that expectations do not explain much of the variation in satisfaction (Williams 1994).

I propose that the older persons are often appropriate assessors of quality of care, as they are the “receivers” who experience the nature of the health and social care. In this thesis the main focus is on the older persons’ perspective. In Papers III and IV older persons’ evaluations of quality of care and, respectively, life satisfaction were analysed, indicating an unambiguous older person’s perspective. In Paper II older persons’ influence on care-planning meetings was analysed, which indirectly reflects the perspective of the older persons. However, their own views of the meetings were not investigated. Organizing integrated care, as expressed in development work, can however mainly be seen as reflecting a provider perspective (Paper I).

Integration

Integration is suggested to be an important attribute of quality of care (Donabedian 1980), which is of particular relevance to primary and municipal care (Campbell *et al.* 2000, Cheng & Lai 2010). Integration can be seen as referring to the effectiveness of professionals’ dealings with other organizations or other professionals, which impact on the outcomes for the individual (Campbell *et al.* 2000). Hvinden (1994) suggested that integrating deals with bringing parts together to make a whole. Integration is related to differentiation, which has been explored by Lawrence *et al.* (1986). They claim that when an organization grows, it will differentiate into parts, which is a natural and needed development. Differentiation means segmentation and specialization, but it also deals with attitudes and behaviour. The functioning of the different parts has to be integrated in order to achieve a viable organization. Integration is seen as the quality of the state of collaboration among departments/organizations that is required to achieve unity of efforts. Furthermore, they stress the necessity of adapting to demands from the environment (Lawrence *et al.* 1986).

Integration is related to other concepts such as co-ordination, co-operation and collaboration. These can be seen as processes which are different aspects and degrees of integration. Co-operation implies working together in order to accomplish the same goal. Collaboration has a similar meaning, but emphasizes working together on a joint task (Hvinden 1994).

Integration can be considered in different ways. It can be described as a range, including different degrees of integration. On the one end is absence of integration or a low degree of integration and on the other end is full integration (Ahgren & Axelsson 2005, Leutz 1999). Another way is to separate integration into two main dimensions: vertical and horizontal integration (Axelsson & Bihari Axelsson 2006, Hvinden 1994). Vertical integration takes place between organizations on different levels of a hierarchical structure, and horizontal integration takes place between organizations on the same level or with the same status (Axelsson & Bihari Axelsson 2006).

Co-ordination is characterized by high vertical and low horizontal integration and management where decisions are made at the top organizational level. Co-operation involves high vertical as well as high horizontal integration and collaboration is characterized by low vertical and high horizontal integration. It is also suggested to add contracting as a form of integration, implying low vertical and low horizontal integra-

		Horizontal integration	
		-	+
Vertical integration	+	Co-ordination	Co-operation
	-	Contracting	Collaboration

Figure 2. Conceptual scheme of different forms of integration (Axelsson and Bihari Axelsson 2006).

tion. The different forms of integration can be combined into a conceptual scheme (Figure 2) (Axelsson & Bihari Axelsson 2006), which is used as an analytical tool in Paper I.

Vertical integration has to do with organizational control over the flow of services in the organization. If horizontal integration is developed synergistic effects may be achieved. This in turn requires interpersonal skills and the resolving of conflicts between departments/organizations as regards the direction of efforts. Furthermore, the more differentiated an organization is, the more difficult it is to achieve integration and the more developed integrating devices are needed (Lawrence *et al.* 1986). Health and social care is highly characterized by differentiation and complexity (Ahgren & Axelsson 2011, Kodner & Spreeuwenberg 2002), which address the need for well-designed and effective forms of integration.

Integrated care

Integrated care has been described as quite a new field, with many meanings, and lacking specificity and clarity. It is equated with managed care in the US, shared care in the UK and transmural care in the Netherlands. Other recognised terms with equal meaning are comprehensive care and disease management. But it is unclear if all these terms really fall under the heading of integrated care (Kodner & Spreeuwenberg 2002). Integration can be considered as a coherent set of methods and models on the funding, administrative, organizational, service delivery and clinical levels. The goal is to enhance quality of care, quality of life and system efficiency for patients with complex, long-term problems, cutting across multiple services, providers and settings. The result of the efforts to promote integration for the benefit of these special patient groups is called “integrated care”. A special patient group includes frail older persons, who have complex and long-term needs (Kodner & Spreeuwenberg 2002).

The methods and models within different levels are named as integrated care strategies. For example a strategy on the level of service delivery is case management, and a strategy on the clinical level is joint care planning (Kodner & Spreeuwenberg 2002). In the above definition, integrated care is seen both as a system or framework in itself and also as the result of efforts promoting integration for the benefit of the older persons. The latter issue gives a positive judgement, that integrated care is something like a desirable condition, where the optimisation for the older persons is in focus. I consider integrated care to be the result of strategies to promote integration within or between organizations, with the goal of benefiting frail older persons.

Care planning and influence

Within the context of care planning interpersonal interactions take place between the older person and several different professionals. Care-planning meetings often constitute a basis for the continuation of care after hospital discharge, which might be of essential importance for the daily lives of the older persons. Therefore their participation in and influence on these meetings is of special importance. Older persons' participation is prescribed in national legislation and regulations (National Board of Health and Welfare 2008b, SFS 1982:763), and conditions for care planning are stated by the National Board of Health and Welfare (SOSFS 2005:27 2005). In addition, Burt *et al.* (2013) stressed older persons' participation in a literature review on care planning. They concluded that care planning is a process where professionals and older persons discuss, agree and review an action plan to achieve the goals or behaviour change of concern to the older person. In this thesis I consider care planning to be a process wherein professionals from the different health and social care organisations co-ordinate the planning of future care, in interaction with the older person and relatives.

In legislation it is prescribed that health and social care shall be designed and delivered in co-operation with the individual person (SFS 1982:763, 2001:453). This involves the person's participation in care, and may also be related to the person's influence. Participation and influence are intertwined concepts, but seem to differ in meaning and understanding. Participation refers mostly to involvement in decision-making, as in the clarification in Mesh (Medical Subject Headings), which is a vocabulary used for indexing articles. In a concept analysis, participation was characterized by an established relationship between the professional and the older person, shared information and knowledge as well as joint active engagement (Sahlsten *et al.* 2008). The definition of participation per se does not necessarily indicate resulting in any following effect. Influence, on the other hand, means that an effect will follow. In this thesis I define influence as the capacity to have an effect on the character or behaviour of someone or something.

Promoting older persons' influence involves several tensions that need to be considered. Hasenfeldt (2010) claims that human service organizations, such as health and social care organizations, seek legitimacy by rules that are grounded in morality, such as divisions of resources and priorities. When older persons need health and social care they are categorized into predetermined "types" and transformed into clients or patients (people processing). Decisions are supposed to be guided by actual knowledge and available resources. These conditions may be frustrating for professionals, if they are not able to use their knowledge due to organizational rules or lack of resources. The competition between different values is reflected in the relationships and the interactions between the professionals and the older persons (Hasenfeldt 2010).

Older persons' influence is strongly associated with power and dependency. The older persons' dependency on care makes the relationships between them and the professionals asymmetrical (Blau 1986, Dunér & Nordström 2010, Lukes 2005). Power involves mainly a dimension of decision-making, but there is also a dimension of non-decision-making, which creates barriers for the older persons and prevents them from having any influence (Beronius 1986, Lukes 2005). To create more equal rela-

tionships a shift is necessary, where the professionals give power and ability to the older persons in empowerment processes (Bradbury-Jones *et al.* 2008, Gibson 1991, Starkey 2003). These processes can take many forms, such as the consumerist model where the older persons are given a choice between predefined services. The liberation model focuses the need of challenging oppression and power asymmetry in the society (Starkey 2003). Finally, a professional practice model involves how professionals can empower the older persons in different ways (Gibson 1991, Starkey 2003).

In addition, behaviour rules contribute to asymmetric relationships (Goffman 1982). Interactions between different persons are under the control of unstated rules set by the character of the situation in which the interactions emerge, which can be called the “frame” (Goffman 1986). A care-planning meeting may be understood as a situation where this frame appears. Some of the persons (i.e. the professionals) define the situation and how to act at the meeting. However, the frame is mostly unfamiliar to the older persons and their relatives, implying their subordinate positions in relation to the professionals.

Life satisfaction

Life satisfaction is closely associated with subjective well-being and quality of life. Subjective well-being is suggested to include moods and emotions as well as cognitive evaluations of life satisfaction (Diener *et al.* 1999). Sirgy (2012) proposed that quality of life is an overarching concept, where global and domain-specific life satisfaction are included. Thus, life satisfaction can be seen as a sub-theme of subjective well-being and quality of life. Sometimes satisfaction with life as a whole is equated with happiness (Fugl-Meyer *et al.* 1991). Level of satisfaction with life as a whole is related to specific domains, such as financial situation, leisure, family life and health (Borg *et al.* 2010, Diener *et al.* 1999). Measurement of life satisfaction is suggested to be used for collecting information in areas where instruments measuring quality of life are weak (Borg *et al.* 2010), such as the social aspects of life.

Previous studies show contradictory results regarding the relationship between life satisfaction and age. Some report that life satisfaction is stable across life (Diener *et al.* 1999, Hamarat *et al.* 2002), while others report a positive relationship between age and life satisfaction (Horley & Lavery 1995, Prenda & Lachman 2001), and yet others a decrease in old age (Berg *et al.* 2009, Mroczek & Spiro 2005). However, life satisfaction among older persons is known to be related to their health (Abu-Bader *et al.* 2003, Borg *et al.* 2008), and frailty has been shown to be of more importance than old age regarding a negative relationship to life satisfaction (Wilhelmson *et al.* 2013). Further, it is important to consider that other conditions influence older persons’ assessment of life satisfaction, such as personality (Berg *et al.* 2009) and personal aspirations in life (Campbell *et al.* 1976).

PARTICIPANTS AND METHODS

Overview of methods

The research questions in this thesis guided the choice of methods. The use of different methods was of special value, and provided conditions for a comprehensive understanding of continuum of care. An overview of the methods included in Papers I-IV is presented in Table 1.

Table 1. Overview of the methods included in Papers I-IV

	Paper I	Paper II	Paper III	Paper IV
Data collection	Reports from R&D-units, the Swedish Association of Local Authorities and Regions and the National Board of Health and Welfare	Audio-recorded care-planning meetings	Face-to-face interviews (questionnaires) at baseline, 3-month, 6-month and 12-month follow-ups	Face-to-face interviews (questionnaires) at baseline, 3-month, 6-month and 12-month follow-ups
Analyses	Meta-analysis of cases, content analysis	Qualitative content analysis	Statistical analyses: Chi-square test Mann-Whitney U-test Wilcoxon Signed Rank Test Friedman test Fisher's Exact Test	Statistical analyses: Chi-square test Mann-Whitney U-test Odds Ratio

Study context

This thesis is part of a larger interdisciplinary intervention project entitled “Continuum of care, from the emergency ward to living at home – Implementation and evaluation of an intervention for frail elderly people” (Duner *et al.* 2011, Hasson 2010, Wilhelmson *et al.* 2011). The study protocol of the project, as well as Papers III and IV, are presented in accordance with the CONSORT recommendations (Consort 2013, Wilhelmson *et al.* 2011, Zwarenstein *et al.* 2008). The project will be referred to as “the intervention project”. The aim of the intervention project was to increase quality of care and maintain functional ability among frail older persons and to increase cost-effectiveness. The project was planned and carried out by researchers from several disciplines. The interdisciplinary approach is in line with ambitions to integrate different disciplines to address challenges that are difficult to accomplish by traditional research approaches. Interdisciplinary research is a growing trend that is assumed to reduce disciplinary barriers and enhance the development of new knowledge (Jacobs & Frickel 2009).

The intervention project took place in a city with approximately 60,000 inhabitants on the west coast of Sweden. It was planned in collaboration between the hospital, primary care and municipal care. The participants (the older persons) were randomly selected either to the intervention group or to the control group. The following methods were performed in the intervention group to establish a comprehensive continuum of care:

- The need for health/social care and rehabilitation was assessed at the emergency department, by a registered nurse with geriatric expertise (two nurses were alternately on duty during the daytime on weekdays).
- If the older person moved to a hospital ward, the assessment was transferred to the ward. In addition, the assessment was transferred to a municipal interprofessional team, including case manager (registered nurse), social worker, physiotherapist and/or occupational therapist.
- The case manager coordinated the planning for discharge, in collaboration with the municipal interprofessional team, hospital professionals and the older person.
- The case manager contacted the relatives, to offer them support and advice and to give them information/involve them in the care planning. This contact was only made if approved by the older person.
- The case manager held a care-planning meeting in the older person's own home, together with the municipal interprofessional team. The meeting took place a few days after discharge, regardless of whether the older person needed home care services or not.
- If the older persons returned home directly after visiting the emergency department, they were offered a care-planning meeting in their homes as well. These meetings took place a few days after the emergency visit.
- Within one week after the care-planning meeting the case manager contacted the older person, for follow-up of needs and care.
- The case manager and the older person made an agreement of how often to follow up the planned care. Usually the case manager contacted the older person at least once a month for twelve months and was available for ongoing support.
- A new care-planning meeting was held in the older person's home after six months, if needed.
- If the older person was admitted to hospital again, a new care-planning meeting in the home was held, after discharge.

In the control group, the older persons received usual care. A care-planning meeting was held at hospital, if new home care services were needed. These meetings were conducted by a regular municipal interprofessional team (social worker, municipal nurse, occupational therapist and/or physiotherapist) and hospital professionals. For

those coming home directly after visiting the emergency department no care-planning meeting was conducted and no information transfer was made from the hospital to the municipality (Hasson *et al.* 2012, Wilhelmson *et al.* 2011).

Inclusion

The participants were recruited at the emergency department by the registered nurses with geriatric expertise during the daytime on weekdays. Those who agreed to participate in the study were randomly selected to either the intervention group or control group. A system of sealed opaque envelopes was used. Inclusion criteria for participating were: age 80 and older or 65 to 79 with at least one chronic illness and a need for assistance in at least one activity of daily living. Exclusion criteria were: severe acute illness (needing assessment and treatment by a physician within ten minutes), dementia or severe cognitive impairment (according to medical records or judgement made by the registered nurses with geriatric expertise at the emergency department) and palliative care (as documented in the medical records) (Wilhelmson *et al.* 2011).

Data collection

Evaluations were made at baseline (a few days after discharge from hospital) and at 3-month, 6-month and 12-month follow-ups. Questionnaires, including validated scales and items, were used and the questions were asked in face-to-face interviews by three PhD students (including myself), project assistants and professionals from the municipal interprofessional team (baseline). The interviews were done in the older persons' own homes. I conducted 65 (mostly 6- and 12-month follow-ups) of about 550 interviews in total. Each interview lasted for about 1.5-3 hours.

Participation was offered to 343 older persons of which 159 (46%) declined participation and 3 were excluded due to dementia. Among those who agreed to participate a few persons died before baseline, and 12 persons in the control group declined to continue participation before baseline. Baseline data were collected for 161 older persons (intervention n=85, control n=76) (Wilhelmson *et al.* 2011). Nine respondents in the intervention group and seven respondents in the control group were lost to follow-up at the 3-month follow-up, as they died or declined to continue. Eight respondents were lost to follow-up at six months in the intervention group and three in the control group. Finally at twelve months, two respondents in the intervention group and seven in the control group were lost to follow-up. Hence, 125 respondents completed the 12-month follow-up (intervention n=66, control n=59) (Figure 3).

Besides questionnaires nineteen care-planning meetings were audio-recorded, at home (intervention group) and in hospital (usual care), which enabled the direct study of decision-making practices and older persons' influence (Paper II). The audio-recordings were made by second author (AD). Independently from the intervention project, data were collected from 62 reports of Research and Development units, the Swedish Association of Local Authorities and Regions as well as the National Board of Health and Welfare (Paper I). The reports comprised different ways to organize integrated care for older persons, which had been carried out in practice. The reports were written by researchers or professional assessors, mostly in order to spread knowledge

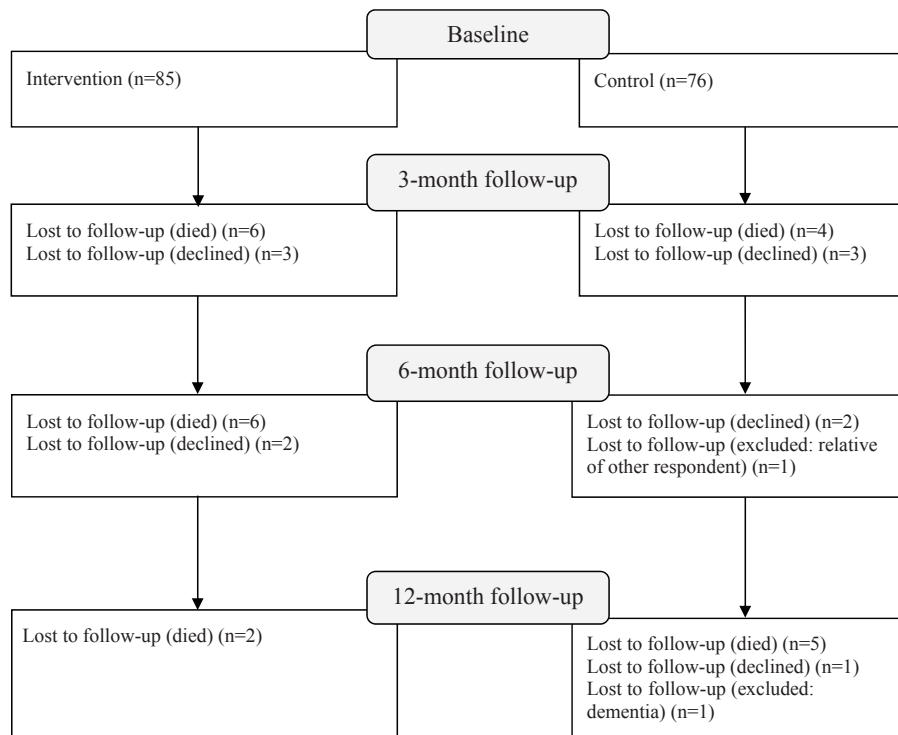


Figure 3. Respondents and drop-outs in the intervention project.

about how to achieve integration within or between organizations. In total the reports included about 2100 pages of text.

Questionnaires

The questionnaires contained validated scales and items on functional ability, health, illness, medication, quality of care and life satisfaction (Wilhelmson *et al.* 2011). The items used in the present analyses were those about older persons' views of quality of care (Paper III) and about older persons' life satisfaction (Paper IV).

The items on older persons' views of quality of care were based on the Pyramid questionnaire. This questionnaire was developed in a hospital setting and showed valid and reliable properties (Arnetz & Arnetz 1996). A modified questionnaire targeting older persons was developed and tested for internal consistency, showing alpha values between 0.69 and 0.80 (Hasson & Arnetz 2008, 2011). The items used in Study III were limited to cover aspects where the intervention was expected to have an effect. Six items concerned care planning, and were asked at the 3-month follow-up. Another item measured older persons' knowledge of whom to contact with questions about the health and social care. This item was asked at all three follow-ups. Three additional items, concerning delivery of health and social care, were asked at the 6- and 12-month follow-ups.

The validated LiSat-11 scale was used to measure older persons' life satisfaction (Borg *et al.* 2010, Fugl-Meyer *et al.* 1991). The scale has been validated in a representative sample of men and women aged 18-74 years (n= 2218) (Borg *et al.* 2010). It has been shown to have adequate test-retest reliability as well as discriminant and specificity validities (Fugl-Meyer *et al.* 1991). The scale contains 11 items: satisfaction with life as a whole and satisfaction with work, financial situation, leisure, friends and acquaintances, sexual life, functional capacity, family life, partner relationship, physical health as well as psychological health (Borg *et al.* 2010, Fugl-Meyer *et al.* 1991). Internal correlation within the Li-Sat-11 items has recently showed that the "life as a whole" item correlates to all other 10 items (Borg *et al.* 2010). Each item includes six response alternatives, ranging from "very dissatisfied" to "very satisfied". The items on satisfaction with work, sexual life as well as partner relationship were excluded in the analysis, due to large amounts of missing values.

Statistics

A power calculation was done, with knowledge of more specific prevalence rates of functional abilities which had been concluded in the "Elderly persons in the risk zone" study (Dahlin-Ivanoff *et al.* 2010). The prevalence rates were for less frail older persons than those in our study, and therefore we anticipated lower functional status and higher standard deviance. This power calculation was based on the Berg Balance Scale, which was one of the primary outcome variables (range 0-56), with an assumed mean for the intervention group of 32 and for the control group of 28 (15% difference), and a standard deviation of 8 in both groups. To be able to detect a difference between the intervention and control groups with a two-sided test and with a significance level of $\alpha = 0.05$ and 80% power, a minimum of 65 persons in each group would be needed (Wilhelmson *et al.* 2011).

In Paper III the Mann-Whitney U-test and Chi-Square Tests were used to calculate differences between the intervention and control groups on baseline characteristics (frailty, gender, age, cohabitant/living alone and dependency in ADL). Differences between groups on respondents' ratings of quality of care were calculated using the Mann-Whitney U-test. This non-parametric test was performed as the two groups were independent from each other, the data were at an ordinal level and we could not assume that data were normally distributed. To estimate differences over time within the respective group, on items measured at the 6- and 12-month follow-ups, the Wilcoxon Signed Rank Test was used and on the item measured at all three follow-ups, the Friedman test was used. These non-parametric tests were relevant as the calculations were based on the same group of persons, and we could not assume that data was normally distributed. The statistical significance level was set at $p < 0.05$ (two-tailed). In addition, the baseline characteristics were checked for those who responded to the respective item, at the 3-, 6- and 12-month follow-ups. The Mann-Whitney U-test and, respectively, Chi-Square Tests were used. If n was less than 30 or if expected frequencies in any cell was less than 5, Fisher's Exact Test was used.

In Paper IV the Mann-Whitney U-test and Chi-Square Tests were used to calculate differences between the intervention and control groups on baseline characteristics (frailty, gender, age, cohabitant/living alone, dependency in ADL and illness). For life

satisfaction, the items were dichotomized into not being satisfied versus being satisfied. Differences between groups on respondents' ratings were calculated as Odds Ratio. Proportions of respondents who were satisfied at baseline and the respective follow-ups were compared between intervention and control groups. Proportions improving or maintaining satisfaction were compared between intervention and control groups from baseline to 3-month, 3-month to 6-month and 6-month to 12-month follow-ups. The proportions from baseline to 6- and 12-month follow-ups were also compared. The baseline characteristics were checked for those who responded and for drop-outs, at all three follow-ups. A two-sided p-value of <0.05 and a 95% confidence interval (CI) were set as statistically significant. All statistical analyses in Paper III and IV were performed using SPSS statistical software package, version 19 for Windows (Chicago: SPSS Inc.).

Intention-to-treat was applied in Paper IV, which comprises an effort to keep the respondents in the groups to which they were randomized. Strategies for dealing with missing data involved imputation of missing values, which means estimating what the value would be if it was not missing (Polit & Gillespie 2010). For respondents who declined to continue before any of the follow-ups the respective median change of deterioration was imputed on each missing value (Eklund *et al.* 2013, Gustafsson *et al.* 2012), as it could be expected that those respondents had deteriorated health. For respondents who died before any of the follow-ups the worst value was imputed to missing cases (Polit & Gillespie 2010). Finally, for internal missing, the respondent's own obtained values on the same outcomes at a different point of time were used. Missing values at baseline were replaced with the values of the outcome for that respondent at the next follow-up. If missing values appeared between two measurements with observed values, a value between these values (mean) was imputed and if they appeared at the 12-month follow-up they were replaced with the values of the outcome at the previous follow-up (Engels & Diehr 2003, Polit 2010).

Content analysis

The audio-recorded care-planning meetings (Paper II) were analysed using qualitative content analysis (Baxter 1994, Krippendorff 2004). The choice of method was guided by the nature of the data, which was collected at authentic settings, as they occurred in practice. The analysis deals with the way people talk in social practice (Silverman 2006). Two domains for analysis were identified. The first domain comprised management of care-planning meetings, including the structure of and interaction in the meetings. The second domain was the content of meetings, including initiatives (issues that were initiated and by whom), discussions (following the initiated issues) and decisions (relating to the initiated issues).

Meaning units of the first domain were identified, condensed and merged into sub-categories and categories. In the analysis of the second domain, meaning units were identified as being initiatives, discussions or decisions. The meaning units were condensed and labelled with codes, which were put together in sub-categories and categories. Independent coding and comparisons were done between me and the second author (AD). After discussions to reach consensus, inter-rater reliability was measured for five of the care-planning meetings. The degree of concordance was 90-96%,

when comparing coding of the content from the meetings. In a final step, overlapping themes on a more abstract level, cutting across categories in both domains, were identified. All authors followed the analysis process, took part in transcriptions and were involved in discussions at regular meetings. NVivo 9 (QSR International, Doncaster, Australia), a qualitative research software program, aimed at helping users organise and analyse non-numerical data, was used.

In addition, older persons' talking space at the meetings was measured by word count (Hedberg *et al.* 2008, Kjellgren *et al.* 2000, Linell 1998), in order to get an approximate measurement of their involvement in the discussions. The use of a quantitative measure within qualitative research can be appropriate in some cases (Silverman 2006), as the space older persons are given to talk in the meetings reflects one aspect of the older persons' influence, which may enrich understanding of the interactions in the meetings.

Meta-analysis of cases

The reports about ways to organize integrated care (Paper I) were analysed using meta-analysis of cases (Yin 2009), including the results from 62 separate cases of development work from Research and Development units, the Swedish Association of Local Authorities and Regions as well as the National Board of Health and Welfare. Characteristics of the cases that were beyond the scope of a separate case were categorized, to create a comprehensive set of features (Yin 2009). Qualitative content analysis was used (Hsieh & Shannon 2005, Patton 2002), involving the conceptual scheme of forms of integration (Axelsson & Bihari Axelsson 2006), in order to sort strategies. Meaning units were identified, condensed, labelled with codes and merged into subcategories, which were then sorted into the conceptual scheme. In addition to the use of the conceptual scheme, the reported goals in the cases were condensed and labelled with codes. Similar codes were merged together into subcategories and categories.

Consensus was reached in coding the strategies to organize integrated care by collaboration with the second author (SB). We discussed in detail how to understand the different forms of integration according to the conceptual scheme (Axelsson & Bihari Axelsson 2006), and how to sort strategies consistently. This procedure of joint coding was done in eight of the cases of development work. I coded the rest of the cases independently, following the same structure. All authors took part in discussions on coding of strategies and goals, during the entire analysis process.

Study periods

The data (questionnaires) for Paper III and IV were collected between October 2008 and October 2011. Audio recordings of care-planning meetings (Paper II) were collected in 2009 and 2010. The data included in Paper I were reports published between 2000 and 2009.

ETHICAL CONSIDERATIONS

The “Continuum of care, from the emergency ward to living at home – Implementation and evaluation of an intervention for frail elderly people” interdisciplinary intervention project was approved by the Regional Ethical Review Board in Gothenburg, Sweden, with registration number 413-08. All older persons who participated signed written informed consent forms. The relatives and professionals who were present at the care-planning meetings in Paper II were informed orally and gave their oral informed consent to participate in the study.

There are some ethical concerns regarding the intervention project that need to be addressed. The questionnaires used at baseline and the three follow-ups were quite extensive, including several tests, scales and items. As it was an interdisciplinary intervention project it was important for the researchers from the different disciplines to include their specific measurement instruments. As a result, the face-to-face interviews required a certain amount of time spent in the older person’s home. There was a risk that this would tire the older person, or cause other inconveniences. This was discussed in the project management group when constructing the questionnaires. The project management group had regular meetings with the interviewers during the project time. In these meetings ethical issues were discussed, such as how to avoid fatigue and inconveniences among the older persons. Techniques that were discussed and performed during the interviews were to take pauses when necessary and to give the older person something to drink etc. In a few cases the interviews were divided up into two occasions, if the older person was too tired to continue. However, missing data were nevertheless sometimes due to the older person being too tired to answer.

RESULTS

The overall aim of the thesis was to explore quality of care for frail older persons, in regard to continuum of care. The results on organizing integrated care (i.e. structure), older persons' influence on care-planning meetings (i.e. process) and their views of quality of care and life satisfaction (i.e. outcome) are given sequentially. An overview of the main results is presented in Table 2.

Table 2. Overview of main results

Structure	Process	Outcome
The strategies involved both enhanced integration but also increased fragmentation. Reported goals focused on steering and designing care and improving integration.	Older persons were not able to influence the way home care services were provided or organized. Nonetheless, care planning at home facilitated older persons' participation in the meetings.	Higher perceived quality of care in intervention group for care planning and knowledge of whom to contact, as compared to control group. Statistically significant odds ratios for satisfaction with functional capacity, psychological health and financial situation, in favour of the intervention.

Structure

The aim of Paper I was to describe and analyse ways of organizing integrated care for older persons in Sweden during the past decade. Several strategies were found in the cases, and they were sorted into the conceptual scheme of different forms of integration (Axelsson & Bihari Axelsson 2006). Co-operation and co-ordination strategies were most common. The strategies are exemplified in Table 3.

Table 3. Examples of strategies in different forms of integration

Co-ordination	Co-operation
Joint agreements Joint management	Local health care system Joint care planning
Contracting	Collaboration
Consumer choice Contracting out	Hospital-based multiprofessional teamwork Primary- or municipal-care-based multiprofessional teamwork

Strategies for co-ordination concerned *joint agreements*, which were often established between organizations in order to clarify the limits and responsibilities for each organization. Sometimes two or more organizations exercised *joint management*, as when they established joint political or operational management groups. Strategies for contracting included *consumer choice*, where the older persons were given the possibility to choose between different public and private care providers. The organizations used *contracting out* to decide which provider should be allowed to deliver care and service, which is intended to create competition between the care providers.

Co-operation strategies comprised the development of *local health care systems*, with focus on new organizational solutions across organizational borders, local care and sometimes medical specialists situated outside the hospital. *Joint care planning* was another strategy, including new structures of care-planning meetings. Finally, collaboration strategies, which were rare in the cases, encompassed *hospital-based* as well as *primary- or municipal-care-based multiprofessional teamwork*. This involved collaboration between geriatricians, general practitioners, registered nurses, district nurses, occupational therapists, physiotherapists and in some cases counsellors and dieticians.

Trends over the past decade were dominated by the development of local health care systems, characterized by enhanced co-operation between organizations, as well as consumer choice models and contracting out. However, consumer choice models turned out to be problematic regarding integration between organizations, and seemed to fragment the provision of care and service.

For the most part, the strategies were elaborated upon after initiation at a high organizational level. In most cases it was not clarified whether the projects continued after project time or not. Thus it was not possible to make any conclusions about which initiators or strategies were more sustainable than others. The goals that were reported in the cases dealt mostly with steering care or improving integration per se. Steering care included decrease of residential living and promotion of living at home. Goals of improving older persons' health or well-being appeared rarely. The methods for evaluation of goals reported in the cases varied greatly. Therefore, it was not feasible to compare goal achievement across the cases and assess which strategies were most successful.

Process

Paper II aimed to describe and analyse older persons' influence on care-planning meetings at home and in hospital. Two domains of the care-planning meetings were identified, the management and the content of care-planning meetings (exemplified in Table 4).

In the first domain different communication strategies were found. The professionals as well as the relatives were *supportive* in the meetings. They tried to back up the older person and listen to his/her wishes. However, they were also *persuasive*, especially when they wanted the older person to accept offered help. Nevertheless, solutions which could be acceptable to both the older persons and the professionals were in many cases developed within *negotiation* processes.

Table 4. Domains and examples of categories and subcategories of results

Domain	Management of care-planning meetings
Category	Communication strategy
Subcategory	Supportive Persuasive Negotiating
Domain	Content of care-planning meetings
Category	Decisions
Subcategory	Accept or reject Non-decisions

In the second domain, the content of the meetings, the results showed that the older persons had influence over concerns dealing with the amount of care/service, such as the frequency of visits from home help service. The older persons were also able to choose providers for some services. On the other hand, they were not able to influence the way the help was to be provided or organised, such as the time of a visit or the number of home care staff providing the help.

At the meetings the professionals presented the municipality's available range of care and services to the older persons, and the older persons could choose what they wanted. They could choose to *accept* the offered help, and decide the amount of care and service, *or reject* the help. When initiatives on the part of the older persons were outside the professionals' predefined agenda or did not match available help, they were often not taken into consideration, and ended up in a *non-decision*. The professionals seemed to be unprepared to deal with unexpected questions' initiated by the older persons, such as issues of an existential nature or issues about the way delivery of care was organized. The professionals were not able to decide about how the help would be provided or organized and they appeared to be bound by the rules of the organisation.

Care-planning meetings at home enabled older persons' participation in the discussions. The older persons' median talking space in the meetings was 40% at home and 20% at hospital. There were fewer persons participating in the meetings at home, less parallel talking and less use of technical or medical terms, as compared to meetings at hospital. Older persons' talking space and number of professionals at the meetings are presented in Table 5.

Table 5. Older persons' talking space (measured as word count) and number of professionals

	Care-planning meetings at home	Care-planning meetings in hospital
Older persons' talking space (per cent of words)		
Range	5-67	11-49
Md	40	20
Professionals in total per meeting (n)	2-4	4-6

Outcome

The aim of Paper III was to analyse frail older persons' views of quality of care when receiving a comprehensive continuum of care intervention, compared to those of persons receiving the usual care (control group). Older persons receiving the intervention perceived higher quality on all items on care planning, based on the Pyramid questionnaire (Arnetz & Arnetz 1996, Hasson & Arnetz 2008, 2011), (see page 2939 in Paper III), as compared to those receiving usual care. The items concerned their participation in the care-planning meetings, responsiveness to individual needs and satisfaction with the care planning. Responsiveness to individual needs concerned the planned home help service, home nursing care and rehabilitation. The value of conducting the care-planning meeting at home was rated higher as compared to the value of conducting the meeting in hospital (control group). The older persons in the intervention group also rated higher on the item concerning their knowledge of whom to contact, at 3- and 12-month follow-ups. However, for the item on satisfaction with care, measured at 6- and 12-month follow-ups, the older persons in the intervention group rated higher as compared to those in the control group, but the differences were not significant.

The combination of intervention services seems to be advantageous for older persons' views of quality of care, based on the Pyramid questionnaire (Arnetz & Arnetz 1996, Hasson & Arnetz 2008, 2011), (see page 2939-40 in Paper III). The intervention included a geriatric assessment at hospital, coordination by a case manager, an inter-professional team, support for relatives as well as care-planning meetings in the older persons' own homes (Hasson 2010, Wilhelmson *et al.* 2011). The result indicates the necessity of measurements of the different aspects of older persons' views of quality of care, as well as distinguishing between planning and delivery of care. The ratings were significantly better in intervention for the planning of care, but no significant differences were detected for the delivery of care (at 6- and 12-month follow-ups).

Paper IV aimed to analyse effects of a comprehensive continuum of care (intervention group) on frail older persons' life satisfaction as compared to those receiving usual care (control group). Three of the life satisfaction items, measured with the LiSat-11 scale (Borg *et al.* 2010, Fugl-Meyer *et al.* 1991), (see page 14-15 in Paper IV), were excluded from analysis, due to a large amount of missing values (these were satisfaction with work, sexual life and partnership). For the remaining eight items there was a pattern of higher proportions of older persons being satisfied in the intervention group at the 12-month follow-up, compared to the control group (for most items it was non-significant).

There were larger proportions of older persons who improved or maintained satisfaction in the intervention group as compared to the control group between 6- and 12-month follow-ups: Satisfaction with functional capacity, psychological health and financial situation showed statistically significant odds ratios in favour of the intervention between 6- and 12-month follow-ups (Table 6).

Table 6. Proportions (%), Odds ratio (OR), 95% Confidence Interval (CI), and p-value for improving or maintaining life satisfaction between 6- and 12-months follow-ups

Satisfaction with	Intervention		Control		95% CI	p-value
	%	OR	%	OR		
Life as a whole	78	1.88	66	1	0.93-3.80	0.08
Financial situation	77	2.08	62	1	1.04-4.14	0.04
Leisure	70	1.31	64	1	0.67-2.54	0.43
Friends and acquaintances	71	1.52	62	1	0.78-2.94	0.22
Functional capacity	75	2.39	55	1	1.22-4.67	0.01
Family life	78	1.50	70	1	0.73-3.10	0.27
Physical health	72	1.61	62	1	0.83-3.14	0.16
Psychological health	78	3.08	54	1	1.55-6.15	0.00

DISCUSSION

The studies included in this thesis showed that organizing integrated care involved a range of strategies and goals, as found in the cases of development work. The strategies included enhanced integration but some strategies also indicated fragmented provision of care. The goals were focused on steering and designing care as well as improving integration. Goals on benefits for the older persons were rarely reported in the cases. The performance of the care-planning meetings, within the intervention project, showed that the older persons were not able to influence the way home care services were provided or organized. However, care planning at home facilitated their participation. Fewer persons were present, there was less parallel talking and the older persons had more talking space. The older persons' own evaluations showed that they perceived higher quality of care in intervention group regarding care planning and knowledge of whom to contact, compared to the control group. Concerning life satisfaction, the older persons in the intervention group were more likely to be satisfied with their functional capacity and psychological health, compared to the control group.

Strategies to organize integrated care

When sorting out the strategies into the conceptual scheme of different forms of vertical and horizontal integration, co-operation and co-ordination strategies were most common, indicating a dominance of vertical integration. Collaboration strategies were rare, which is noteworthy, as horizontal integration is considered essential in highly differentiated organizations (Axelsson & Bihari Axelsson 2006, Lawrence *et al.* 1986), such as health and social care.

The trends over the decade comprised contradictory strategies. On the one hand, the development of local health care systems implies a direction towards enhanced integration and an ambition to create comprehensive systems. On the other hand, the trend of consumer choice and contracting out appeared to complicate integration. The number of actors in the continuum of care increases, but they seem to lack unity of efforts. However, Ahgren (2010) suggests that consumer choice and local health care systems can be combined. If local health care systems are developed, the older persons could choose among these systems rather than among individual care providers.

The inclusion of contracting in the scheme of different forms of integration can be questioned. Contracting reflects low vertical and low horizontal integration, implying a lack of integration rather than a form of integration. Contracting strategies are not included in the overview of strategies by Kodner & Spreeuwenberg (2002). Leichsenring (2004) claims that such strategies need preconditions, such as combining them with case management and efforts to empower the older persons. However, the inclusion of contracting might be seen as reflecting a whole view of the complexity of integration, including absence of integration and different amounts of vertical and horizontal integration.

Other ways to consider integration imply that lack of integration is relevant when integration is not required. This is the case when a sole provider is able to fulfil the

needs of a particular group or when the provider does not have to rely on other providers (Ahgren 2012, Leutz 1999). However, care for frail older persons requires a high degree of integration, as it is highly differentiated into parts (Lawrence *et al.* 1986).

The identified strategies in the cases were mostly initiated at the top organizational level. This is of interest to note, especially as initiation at the local level has been shown to increase the chances of successful results (Ahgren & Axelsson 2007). Bottom-up approaches accounting the local contexts are considered to be key issues for sustainable solutions (Goodwin *et al.* 2013). In addition, many projects were dependent on special funds and the care providers changed priorities during the project time (National Board of Health and Welfare 2009b). However, it was most often not reported whether the respective strategy continued after project time or not, i.e. if the initiatives resulted in sustainable strategies. In any case, the distribution of special funds in the coming years will focus on establishing integrated care for frail older persons, rather than on starting new projects (Ministry of Health and Social Affairs 2012).

The goals stated in the cases were focused on steering and designing care, in the direction pointed out in national reforms and policies. Moreover, to improve integration was commonly expressed as a goal, which reflects the positive symbolic value of integration and the organizations' adaptation to expectations in society (Trägårdh & Lindberg 2004, Wistow & Dickinson 2012). Regarding integration as a goal in itself contradicts the very intent of integrated care, i.e. to obtain a result of strategies which benefits frail older persons (Kodner & Spreeuwenberg 2002). Most cases included goals that benefit the provider, rather than the older person. It was rare to find goals that comprised fulfilment of older persons' needs or enhanced health or well-being. Nonetheless, a study on development of integrated care suggested that organizing integrated care primarily aims to meet the needs of frail older persons (Dubuc *et al.* 2013). Furthermore, older persons' perspective of quality of care includes the extent to which the care system provides the structure and process that meet the needs of older persons and the extent to which care delivers an outcome in response to needs (Campbell *et al.* 2000). Nevertheless, goals focused on steering, designing and integrating care might indirectly result in positive outcomes for the older persons, which was probably the intention of the initiators.

This points out the importance of recognizing the interdependence between structure and outcome, as regards quality of care. I still do not know to what extent the strategies were performed or if the goals were fulfilled, as this was often not documented in the reports. Therefore it was not possible to draw conclusions of links between strategies and outcomes. However, local health care systems were shown to enhance integration, while consumer choice and contracting out appeared to inhibit integration between organizations.

The limits of frail older persons' influence

One of the strategies in the intervention project was care-planning meetings in the older persons' homes. It became evident that the older persons' influence was affected by the prevailing structural conditions. Regardless of where the meeting took place the professionals defined the situation and controlled the agenda of the meetings. This

could result in a non-decision, if the issue was beyond the “possible” issues for the meeting. Besides decision-making, agenda control and non-decision-making constitute an important dimension of power (Beronius 1986, Lukes 2005). These results indicate a classification in predefined categories, which is a characteristic of processing procedures within human service organisations (Dunér & Nordström 2009, Hasenfeld 2010). Organisational rules obstructed the older persons’ influence over needs assessment and decisions on home care, especially regarding home help services, which was also found in previous studies (Blomberg & Petersson 2007, Dunér & Nordström 2006, Olaison & Cedersund 2006, Sullivan 2009). As a result, there is a risk that a comprehensive view of individual needs and care is not taken. Rydeman *et al.* (2012) showed that older persons felt that their entire complex situation was not taken into consideration in care planning. As a consequence, health and well-being processes risk being inhibited (Dahlberg *et al.* 2009, Efraimsson *et al.* 2006).

As home care services are quite standardized and regulated by the organizations (Blomberg & Petersson 2007, Dunér & Nordström 2006, Janlov *et al.* 2006) it is important to acknowledge that the structural conditions also delimit the professionals’ power in making individual solutions (Adams 2008). Consequently, the difficulties of empowering older persons to influence decision-making (Bradbury-Jones *et al.* 2008) was confirmed in the care-planning meetings. The restricted influence may lead to concerns for the older persons, dealing with needs that are not fulfilled. However, it was shown that the professionals used negotiations in order to find solutions that could be accepted by the older persons within existing structural conditions. Processes of negotiation were also observed in similar studies (Cedersund & Olaison 2010, Dunér & Nordström 2010), as part of the interaction between the older person and the professionals. Furthermore, Kvarnström *et al.* (2013) found that negotiation is part of professionals’ perceptions about older persons’ or other users’ participation, focusing on adjusting aspects. Additionally, the professionals used their respective expertises, and collaborated with each other in order to find appropriate solutions. However, interprofessional teamwork may also include contradictory aspects, as when the professionals form alliances to convince the older person to accept their solutions (Goffman 1986, Manthorpe 2003), which could be seen in some care-planning meetings.

During the care-planning meetings, some of the older persons referred to earlier experiences of expressing dissatisfaction with services, and questioned their possibility of influence. Instead, the older persons and/or their relatives often accepted the help they could get, reflecting their dependence and the power of the professionals and the organization (Blau 1986, Lukes 2005). At times, the older persons abstained from home care they did not regard as meeting their needs, as described in earlier studies (Dunér & Nordström 2010, Hardy *et al.* 1999). This was the case if they were less dependent upon help from elderly care, as they could obtain help from other sources or, in few cases, had the opportunity to manage without help.

Previous studies on older persons’ participation and influence in the context of care planning have shown that frail older persons do not participate much in decision-making about discharge from hospital (Ekdahl *et al.* 2012) or discussions about goal-setting (Almborg *et al.* 2009, Furaker *et al.* 2004, Huby *et al.* 2004). As found in earlier studies, the professionals dominate the communication at care-planning meetings

(Efraimsson *et al.* 2003, Hedberg *et al.* 2008). However, when care-planning meetings were held in the older persons' homes the conditions for their participation were more beneficial to them. They had more talking space, parallel talking occurred rarely and fewer professionals participated as compared to meetings at hospital. The hospital meetings were used as an arena for sharing information between professionals, rather than sharing information with the older persons. This is noteworthy, as information-sharing between the older persons and the professionals is considered an essential basis in the decision-making process (Donnelly *et al.* 2013). However, it is difficult to compare these findings with those of other studies, as there is a lack of previous studies including care-planning meetings in older persons' own homes.

Positive evaluations by the frail older persons

The older persons rated higher participation when care-planning meetings were held at home, probably as they experienced a peaceful atmosphere, with fewer persons present. This is supported by the study on the older persons' influence (Paper II), showing better conditions for the older persons to take part in the discussions. The co-ordination by the case manager probably also contributed to the older persons' positive evaluations of their participation.

Those older persons who received the intervention rated better response to their individual needs, as compared to those receiving usual care. This indicates that they felt confident with the professionals in assessing their needs. It is likely that the assessment at the emergency department, the co-ordination by the case manager, the interprofessional teamwork and the fact that the meeting was held at home led to this result. Each professional made contributions in line with their respective skills and expertises, resulting in enhanced possibilities of a comprehensive view of the older persons' abilities and needs.

The positive effects on older persons' evaluations of participation and responsiveness to individual needs can be supported by previous studies, that have similar approaches. Preen *et al.* (2005) found higher ratings of participation among older persons when a designated registered nurse/coordinator conducted the care planning. In a literature review on person-centred interventions, including assessment of medical, functional and psychosocial needs and multiple home visits by skilled nurses, it was shown that the mutual trust and empathy with the older persons helped to identify potential problems and unmet care needs (Liebel *et al.* 2009). However, it is important to consider whether high ratings on participation and responsiveness to individual needs in the present study also imply that the older persons had the opportunity of real influence and of receiving individual care solutions. Instead, it may be that the older persons received the available care that best matched their needs, as concluded in the study on older persons' influence at the meeting, as well as in similar studies (Foster *et al.* 2006, Janlov *et al.* 2006).

The older persons in the intervention group also rated greater overall satisfaction with the care-planning meetings. Other studies including individually tailored care plans, mostly conducted by a coordinator/case manager, showed greater satisfaction as compared to that of control groups (Preen *et al.* 2005, Shepperd *et al.* 2010, Shepperd *et*

al. 2013). Preyde *et al.* (2009) showed that continuum of care interventions including a coordinator/case manager who conducted the care planning as well as interprofessional teamwork had a positive effect on older persons' satisfaction. In these cases the care-planning meetings were not performed in the older persons' homes, indicating that co-ordination by a case manager is an important strategy for older persons' satisfaction, regardless of where the meetings are held. In addition, the intervention *per se*, in the present study, may have contributed to older persons' satisfaction with care planning, as they received a lot of attention and felt that the professionals made thorough assessments.

The older persons in the intervention group also rated better knowledge of whom to contact than did those in the control group, at 3- and 12-month follow-ups. It was probably more convenient for the older persons to have one person to keep in mind, who could be contacted (i.e. the case manager), rather than having several different professionals, as in the control group. This finding is in line with another study, including geriatric assessment and a case manager who did the care planning, showing better knowledge among the older persons of whom to contact with questions (Dedhia *et al.* 2009).

However, in the present study significant differences between the groups could not be detected regarding older persons' satisfaction with delivery of care, at 6- or 12-month follow-ups. It seems that further interventions are needed in order to obtain more long-term satisfaction. It might be that those who deliver care and service should be more involved, involving support with education and training programmes. In addition, more frequent follow-ups by the case manager may be needed. It could also be that the project needs to become part of the usual care, in order to create sustainable methods. This is supported by studies of a systematic integrated care policy, including case management, which has gone on for several years. Over four years, satisfaction with delivery of care improved, whereas it did not change in a control group (Hébert *et al.* 2010, Stewart *et al.* 2013).

The intervention had a positive effect on older persons' satisfaction with functional capacity, psychological health and financial situation. It is reasonable that the interprofessional team contributed to the positive effects on older persons' satisfaction with functional capacity. A physiotherapist and/or occupational therapist participated in care planning in the older persons' own homes. They paid attention to how the older persons managed in their daily living at home and ensured that they received suitable rehabilitation and technical aids. The assessment of need for health/social care and rehabilitation made at the emergency department as well as the co-ordination and follow-ups made by the case manager probably also contributed to the positive results. The result is in line with another study in the intervention project, showing that objective measurement of functional capacity (ADL independence) improved in the intervention group (Eklund *et al.* 2013).

The positive results on satisfaction with psychological health might be a consequence of the older persons' positive views of quality of care in the intervention project. The older persons felt satisfied with the care-planning meetings in their homes and they knew better whom to contact, which probably made them feel comfortable and secure.

The positive effects on older persons' satisfaction with their financial situations may in turn be a result of better psychological health. The older persons probably adjusted their preferences to their current financial situations.

However, there seems to be a lack of interventions where life satisfaction is evaluated, which makes it difficult to compare the findings with other studies. Instead quality of life or subjective well-being were measured in previous studies, with ambiguous findings. Beneficial effects on quality of life has been shown in studies including individualized, comprehensive care planning and post-discharge home visits (Lin *et al.* 2009) as well as augmented care planning with designated care coordinators and interprofessional teams (Preyde *et al.* 2009). Another study including individualized care planning managed by a coordinator showed no effect on quality of life (Weinberger *et al.* 1996) and an intervention including augmented care planning and interprofessional co-ordination showed better quality of life in the control group (Sulch *et al.* 2000). However, in a systematic review of studies including care planning and co-ordination by a case manager consistent evidence could be shown regarding improvements on older persons' subjective well-being (You *et al.* 2012).

Furthermore, satisfaction with functional capacity, psychological health and financial situation are interconnected and are known to correlate with overall life satisfaction (Borg *et al.* 2010). Enkvist *et al.* (2012) found that reduced functional capacity, assessed as ADL levels, led to lower life satisfaction among older persons aged 78 and over. Decrease in functional capacity appears in turn to be related to low degrees of psychological health. Deterioration of ADL levels has been found to be associated with worry and depression (Bowling & Grundy 1997), and worry as well as depressive symptoms have been shown to be related to lower levels of life satisfaction (Berg *et al.* 2009, Borg *et al.* 2008). In addition, Berg *et al.* (2009) showed that financial situation and life satisfaction were related, on a cross-sectional level.

Quality in the continuum of care

The quality of care approaches of structure, process and outcome, as they appear in the continuum of care, were examined in this thesis. In the study on organizing integrated care, opinions by policymakers and managers became evident, involving an idea that quality of care can be organized per se, which reflects a provider perspective on quality of care.

The relations between structure, process and outcome can to some extent be illuminated in the intervention project. The findings imply that the interactions taking place at care-planning meetings (i.e. process) can be developed by changes in the organizational conditions (i.e. structure), such as organizing the meetings in the older persons' homes. The fact that the care-planning meetings were held in the older persons' homes constituted an organizational condition that was shown to promote older persons' participation. However, other aspects of structure such as organizational rules and guidelines appeared to inhibit older persons' influence.

The organization of the resources in the intervention project constituted the conditions for practice and performance of health and social care. The cause of the outcomes on

older persons' evaluations is probably a combination of the organizational conditions in the intervention project (i.e. structure) and the actual way the professionals operationalized their roles in the different settings and situations (i.e. process). The older persons in the intervention group perceived higher participation, higher responsiveness to individual needs and higher satisfaction with care planning as well as better knowledge of whom to contact as compared to the control group (i.e. outcome). This is most certainly related to the organizational conditions inherent in the intervention and the way the professionals performed the geriatric assessment and the care-planning meetings with the case manager and the interprofessional team. In addition, the positive effect on life satisfaction (i.e. outcome) is probably a consequence of the professionals' performance as well as the older persons' positive evaluations of quality of care. Their view of higher quality of care as regards care planning and better knowledge of whom to contact may have contributed to feelings of comfort and well-being.

Nevertheless, the interdependence between structure, process and outcome constitutes complicated relations, and can probably not be fully understood. In the literature there seems to be consensus on the fact that structure first of all influences process, and process in turn has the most influence on outcomes (Donabedian 1980, 2003, Gardner *et al.* 2014), indicating the importance of performing health and social care according to the frail older persons' individual abilities and needs.

Methodological considerations

My own background played an essential role when initiating this thesis. I worked for several years as a registered nurse, as a medically responsible nurse as well as manager within medical intensive care, elderly care and home nursing care. I have experienced the problems of poor co-ordination between care providers, especially regarding older persons with complex needs. In addition, when I worked in a geriatric clinic in Switzerland I noticed similar conditions. Writing this thesis gives me an opportunity to contribute to the understanding of the continuum of care and of how to explore improvement possibilities.

Limitations

A limitation in the design of the intervention project was that the baseline measurement was made shortly after the intervention had started. This was done as it was considered to be ethically incorrect to tire the older persons with the extensive questionnaires at the emergency department. Therefore the baseline measurement was made shortly after hospital discharge, in the older persons' own homes. This methodological problem became obvious in Paper IV, as the intervention had some effect on life satisfaction already at the baseline measurement. This is discussed in detail in Paper IV.

Internal validity

In the intervention project some persons died or declined to continue participation during the study period, which could have posed a risk to the internal validity. Additionally, some items used in Paper III had low response rates, due to the item not being relevant, as the older persons did not receive the corresponding service. However, base-line characteristics (age, gender, cohabitant/living alone, I-ADL/P-ADL

and frailty) were checked for those who responded to the respective item, at 3- 6- and 12-month follow-ups. There were no significant differences between the groups on any of the follow-up occasions (each item was analysed).

In Paper IV the drop-out rates were 15-22% at the 3-, 6- and 12-month follow-ups. There were no significant differences in baseline characteristics between respondents who completed all follow-ups and the drop-outs, as regards age, gender, cohabitant/living alone and illness. However, there was a pattern of higher baseline illness (≥ 2 severe/constant disability or extremely severe clinical problem) in drop-outs at all three follow-ups, but the differences were non-significant. For baseline I-ADL/P-ADL there were larger proportions in drop-outs regarding dependency in ≥ 1 activity at all follow-ups, but these differences were only significant for I-ADL at the 3- and 12-month follow-ups (about 70% for respondents and about 95% for drop-outs). This indicates that the drop-outs were not random. The drop-outs appeared to be those who had deteriorated health/reduced functional ability and were too tired to continue (or died). Our choice of imputation method for missing values for those who declined to continue (median change of deterioration was imputed) or died (worst value was imputed) seems therefore to be appropriate. Analyzing only complete cases would not have been appropriate, as it could lead to bias and threatening of the internal validity, especially when missing data were not random (Polit 2010).

External validity

The Pyramid questionnaire, from which items were used in Paper III, is well-established and has been validated in previous studies. The original questionnaire was developed in a hospital setting, demonstrating valid properties (Arnetz & Arnetz 1996). It was modified to target older persons within hospital and municipal care, and demonstrated good validity (Hasson 2006). The LiSat-11 scale used in Paper IV is also well-established and has been validated in previous research. The LiSat-11 scale was however not developed to target older persons. This was noted, as the items on satisfaction with work, sexual life and partnership had large amounts of missing values. These aspects of life seemed to be irrelevant for many of the older persons in our study. However, this did not cause any major problems, as we excluded those items and analysed only the rest of the items. In a previous study it was concluded that the scale is applicable on older persons, but probably more sensitive in a younger population (Wilhelmson *et al.* 2013).

Another issue concerns how we know that the findings were due to the components that were planned for the intervention project (Wilhelmson *et al.* 2011), and if the findings would be replicable. Professionals do not always act as intended, for several reasons (Burns & Grove 2001, Dunér & Nordström 2006). However, in an implementation study on the intervention project it was shown that most intervention components were to a great extent delivered as planned. The components that were not always delivered as planned concerned the location for the geriatric assessment at hospital. The assessment was planned to be made at the emergency department, but in most cases the nurses with geriatric expertise made it at the ward. Therefore, the professionals at the wards may not have used the assessment as the basis for their planning, as it was delivered to them when the older persons were already in the wards (Hasson *et*

al. 2012). However, this probably did not have any major impact on the continuation of the intervention, as both hospital professionals and the municipal interprofessional team had access to the assessment. In addition, a few components were added. Members in the municipal interprofessional team started, beside planning rehabilitation, to conduct rehabilitation for the older persons, as the usual rehabilitation professionals had long waiting lists (Hasson *et al.* 2012). This could have generated an increased satisfaction with rehabilitation in favour of the intervention, as assessed in Paper III.

Reliability

Regarding the Pyramid questionnaire, the reliability has previously been estimated concerning homogeneity, addressing the correlation of items within the measurement instruments (Burns & Grove 2001, Streiner & Norman 2008). The Pyramid questionnaire has shown sufficient alpha values (Hasson & Arnetz 2008, 2011). As regards the LiSat-11 scale, a test-retest was estimated, showing adequate reliability (Fugl-Meyer *et al.* 1991).

As the intervention project included several interview occasions and lasted for a total period of about three years there were several interviewers involved. Various steps were taken to minimize errors in the measurements. The interviewers were introduced by accompanying another interviewer to the older person's home, to learn how to use the questionnaires. All interviewers had access to a manual including clarifications and descriptions of the meaning of scales and items. In addition regular meetings were held among the interviewers and project managers in order to reach consensus about meaning. The respective interviewer entered collected data into a database. To secure that correct values from the questionnaires were entered, they were verified by another person than the one who collected and entered the data. A logbook was used to document adjustments.

Additionally, care planning involves registered nurses, social workers, occupational therapists, physiotherapists and sometimes home help aides. Several different professionals also act in the care delivery, which makes it difficult to make inferences about exactly which contributions lead to specific outcomes, as measured in Papers III and IV. This is also concluded by Burns & Grove (2001), who highlighted the complexity of evaluating contributions by several professionals or a team. However, in Paper III most items were specified concerning home help service, home nursing care and rehabilitation.

Trustworthiness in qualitative research

Coding of texts, such as documented cases of development work (Paper I) and transcriptions of care-planning meetings (Paper II), may include different judgements by different persons. There is some subjectivity inherent in qualitative studies, and the meaning derived from the analysis is dependent on the skill used in conducting the analysis (Burns & Grove 2001). This highlights the importance of transparency in the analysis process. The aspect of reliability was improved by the steps taken in collaboration with the co-authors in Papers I and II. In Paper I consensus was reached by initial joint coding of strategies, where the main idea and starting point in the respective case was focused. The following independent coding was made with the same focus,

which ensured consequence and sufficient accuracy in the coding process. In Paper II the aspect of equivalence was focused by comparing the coding of two observers (Burns & Grove 2001), showing a sufficient degree of concordance in coding between the first and second authors.

Credibility, which is suggested to be a criterion of trustworthiness within qualitative research, means that confidence in the “truth” of the findings needs to be established (Lincoln & Guba 1985). To enhance credibility the coding processes in Papers I and II were described carefully, which makes it possible to reconstruct the steps taken. To clarify the coding processes all categories were illustrated by examples.

Authenticity of care-planning meetings

In addition, the aspect of authenticity of the data, concerning the audio-recorded care-planning meetings, needs to be addressed. A researcher was present at the meetings to make the audio recordings. There is a risk that this may have affected the interactions between the involved actors (Miles & Huberman 1994). However, it is reasonable that the actors in the meetings did not pay much attention to the researcher as they were occupied with their own tasks at the meetings, implying that the meetings probably represent naturally occurring interactions.

CONCLUSIONS

Strategies including vertical integration have dominated development works in Sweden during the past decade. The development of local health care systems appeared to be a promising strategy, while contracting strategies seemed to be problematic regarding integration between organizations. Furthermore, the goals in the development works were often expressed generally, and they focused on a care providers' perspective rather than on the older persons' perspective. Mostly it was not documented if the strategies were incorporated into usual care and goal achievements were not consistently measured, which made it difficult to assess which strategies were most successful.

Quality in the continuum of care for frail older persons could be enhanced by an intervention, including assessment at the emergency department, a municipal case manager, interprofessional teamwork and the organizing of care-planning meetings in the older persons' homes. The intervention had a positive effect on older persons' own evaluations of quality of care. Those who received the intervention rated higher quality concerning care planning and they also had better knowledge of whom to contact with questions about health and social care. However, it seems to demand further efforts to obtain more long-term effects on older persons' evaluations of delivery of care, as these questions showed no statistically significant differences between intervention and control groups (at 6- and 12-month follow-ups). Moreover, care-planning meetings in the homes appeared to be an enabling condition concerning older persons' participation. Nevertheless, their possibilities to obtain real influence over the way to deliver or organize home care appeared to be restricted by organizational rules, regardless of where the meeting took place. In addition, the intervention had a positive effect on frail older persons' life satisfaction, especially regarding satisfaction with functional capacity and psychological health.

IMPLICATIONS

In order to make solid evaluations of projects it seems important to consider the need of setting specific goals. Furthermore, when applicable, it would probably be more beneficial for the older persons if goals are built more on their perspectives. They are the “users” of the care system, and ultimately the changes in organizing integrated care should aim to benefit this group. In addition, it is important to note the risk that special funds prioritize short-term solutions rather than more sustainable solutions.

The current system emphasizes standardized care solutions and choice between different providers, which risks neglect of essential aspects of older persons’ influence over the planning and delivery of health and social care. There is a need to discuss the professionals’ possibilities to make decisions in accordance with the older persons’ needs and wishes. Additionally, policymakers, managers and professionals are suggested to further promote the establishment of comprehensive continuum of care for frail older persons, in order to enhance quality of care.

FUTURE RESEARCH

- It is of interest to further study the results and consequences of local health care systems as well as consumer choice and contracting out, for frail older persons and for the integration between organizations.
- Empirical studies are also needed in order to test and develop integration theory.
- Care-planning meetings in the older persons' own homes need to be further evaluated.
- Frail older persons' perspectives on what constitutes good quality of care should be examined, to better adjust the organization to their abilities and needs.

SVENSK SAMMANFATTNING

Denna avhandling handlar om vårdkvalitet för sköra äldre personer, dvs. personer med nedsatt "reservkapacitet" och risk för funktionshinder och sjuklighet. Dessa personer är ofta i behov av vård och omsorg från flera olika vårdgivare (sjukhusvård, primärvård och kommunal vård och omsorg). Hemtjänst bedrivs inom kommunens ansvarsområde och hemsjukvård bedrivs ibland av primärvården, men det pågår en överföring till kommunal regi. Begreppet vårdkedja brukar användas för att beskriva den sammanhållande vård som behövs när den äldre personen kommer i kontakt med olika vårdgivare. I denna avhandling fokuseras olika aspekter på vårdkvalitet som berör struktur (organisering av vårdkedja), process (den äldre personens inflytande vid vårdplanering) samt resultat (den äldre personens bedömning av vårdkvalitet samt livstillfredsställelse).

Organisering av vårdkedjan i Sverige undersöktes genom en analys av 62 rapporter från Forsknings- och utvecklingsenheter, Socialstyrelsen och Sveriges Kommuner och Landsting (Studie I). Utgångspunkten i analysen var en teoretisk modell för integration, som inbegrep samordning, kontraktsstyrning, samverkan och samarbete. Strategier för samverkan, såsom närvårdssystem var vanliga, medan strategier för samarbete, såsom interprofessionellt teamarbete var mer sällsynt. Kontraktering kan ifrågasättas som en form av integration, då t ex kundvalsmodellen som strategi verkar komplicera integration mellan organisationer. Målen som beskrevs i rapporterna handlade om att styra och utforma vården, snarare än att ge något resultat eller mervärde för de äldre personerna. Ofta var målet att förbättra samverkan i sig, vilket troligtvis uttalades för att tillgodose förväntningar från omgivningen. Målen var ofta bristfälligt utvärderade och vanligtvis framgick det inte om utvecklingsarbetena hade införts i ordinarie verksamhet. Därför var det inte möjligt att dra några slutsatser om vilka strategier som var mest framgångsrika eller hållbara. Denna studie bidrar till förståelsen av hur olika strategier har utvecklats för att organisera vårdkedjan samt lyfter fram relationen mellan teori och praxis. Den visar på behovet av att fastställa uppföljningsbara mål och att utvärdera resultaten.

För att förbättra vårdkvaliteten genomfördes ett interventionsprojekt med nya metoder i vårdkedjan. Interventionen innebar: bedömning av sjuksköterska med geriatrisk kompetens vid sjukhusets akutmottagning, case manager (sjuksköterska) i kommunen som samordnade all planering inför utskrivning och kontinuerligt följde upp vården i hemmet, interprofessionellt team i kommunen (case manager, biståndshandläggare, arbetsterapeut och/eller sjukgymnast), vårdplanering i den äldre personens hem samt stöd till anhöriga. Sammanlagt deltog 161 äldre personer i projektet (85 personer deltog i interventionen och 76 fick vanlig vård.). Uppföljning med frågeformulär gjordes i samband med hemkomsten från sjukhuset (baslinjemätning) samt efter 3, 6 och 12 månader. Frågeformulären innehöll validerade instrument som mätte hälsa, livstillfredsställelse och de äldres bedömning av vårdkvalitet.

De äldres bedömning av vårdkvaliteten var signifikant bättre bland dem som deltog i interventionen när det gällde vårdplanering och kunskap om vem man ska vända sig till (Studie III). Däremot kunde man inte se några skillnader när det gällde de äldres

bedömning av kvaliteten på utförandet av vården och omsorgen i hemmet, efter 6 och 12 månader. Det tycks vara svårare att uppnå långsiktig effekt och det krävs troligen ytterligare åtgärder för att uppnå detta. De äldres livstillfredsställelse påverkades till viss del av interventionen. Det var en större andel av de äldre som förbättrade/bibehöll sin tillfredsställelse med framförallt funktionsförmåga och psykologisk hälsa (Studie IV).

För att undersöka de äldre personernas inflytande vid vårdplaneringar gjordes ljudinspelningar av 19 vårdplaneringsmöten, varav 10 utfördes i hemmet (interventionen) och 9 på sjukhus (vanlig vård) (Studie II). Vid möten i hemmet var de äldre mer delaktiga i diskussionerna jämfört med vid möten på sjukhuset. De fick bättre möjlighet att göra sin röst hörd och färre personer deltog på mötena. Oavsett var mötet ägde rum hade de äldre inflytande över omfattningen av vård och omsorg i hemmet och de kunde välja utförare för vissa tjänster. Däremot hade de inte inflytande över hur vården och omsorgen skulle genomföras (t ex vilka tider hjälpen skulle ges eller hur många olika personer som skulle komma hem). Agendan för mötena var förbestämd och när de äldre initierade frågor som inte ”ingick” i agendan togs de ofta inte i beaktande. De äldres delaktighet i diskussionerna gynnades vid möten i hemmet, men det tycks inte vara tillräckligt för att uppnå verkligt inflytande. Studien visar att det behövs ökad uppmärksamhet och diskussion kring hur äldre personer kan få ökat inflytande över den dagliga vården och omsorgen i hemmet.

Sammanfattningsvis visar avhandlingen att en kombination av flera metoder, såsom samordning av en case manager, interprofessionellt teamarbete och utförande av vårdplanering i hemmet har en gynnsam effekt på de äldres bedömning av vårdkvaliteten, framförallt när det gäller vårdplanering. Vårdplanering i hemmet gynnar de äldres möjligheter till delaktighet, men är inte tillräckligt för att uppnå verkligt inflytande över den dagliga vården och omsorgen.

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