

Annual report 2004

Collaborative and integrated approaches to health 1:2005

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Forskningsplattformen för utveckling av Närsjukvård är ett samarbete mellan:

Bromölla kommun, Hässleholms kommun, Kristianstad kommun,
Osby kommun, Perstorps kommun, Östra Göinge kommun samt:



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1. Introduction

This is the first annual academic report of the Forskningsplattformen for Närsjukvård. It covers a time period of slightly over one year. It aims to summarize the progress of the research being undertaken under the umbrella of the Platform during the period since it started. The report contains two parts. The first part consists of a general overview. The second part contains individual reports of the six current research initiatives associated with the platform.

1.1 Origin of the platform

The notion of a research platform to support the development of Närsjukvård was originally put forward by Höskolan Kristianstad and north east Skåne's health care district together, to the Regional Council of Skåne in 2001 (Region Skåne och Höskolan Kristianstad, 2002). It had a number of aims. Firstly, to support new developments in community care which focus in partnership working between a range of services, secondly, to support the development of a new culture of care where the focus is on the client/ patient and their families and thirdly contribute to the promotion of health and well being with a particular focus on the elderly, palliative care and health promotion for children and young people.

Höskolan Kristianstad was made responsible for developing the platform and Region Skåne north east and the municipal healthcare in the six municipalities of northeast Skåne (Kristianstad, Hässleholm, Bromölla, Osby, Perstorp, Östra Göinge) for developing networks and arenas where collaboration could take place. During the initial years, the platform is funded by Region Skåne for researchers and PhD students and by Höskolan Kristianstad for professors, facilities and lecturers. All the staff associated with the platform work only part of their time on the platform's research.

The six research initiatives described in this report:

1. Evaluation of Närsjukvård Initiative consists of a number of related elements covering this initiative of three working groups on stroke, heart failure and wound care and staff in the hospital ward devoted to Närsjukvård in Hässleholm. An internal evaluation is also being undertaken and the change process is being supported by Stockholm University and the FoU Skåne Kommunförbundet. This platform is focusing on health system change at group and system level and patient involvement in decision making with regard to their care.
2. Family health in Näsby comprises two initiatives, one concerned with research which is supporting the development of the new family centre and the other with researching the health needs of immigrant women who access services in the primary care centre. The latter research has only just commenced.
3. Community Care in Bromölla comprises a number of related projects all focussing on community care for the chronically ill.
4. Evaluation of the FoU Närsjukvård network is a research project looking at the role of research and development clinical networks in the development of health system change.

5. Fenix is a support programme for people having or who have recovered from Cancer consisting of educational and other programmes, the research is helping with the development of appropriate support programmes for the families and carers.
6. Evaluation of collaboration in provision of Psychiatric Care. Initially this research explored the collaboration between different elements of the psychiatric service for children and adults. Discussions are currently under way as to the future direction of the research.

2. Part One

Overview of Research

2.1 Working together on research to develop local knowledge and practice

According to Skånsk Livskraft – vård och hälsa, the vision of Närsjukvård is one of finding new ways of working involving collaboration between different services, people and organizations. This platform reflects this agenda both in its own way of working and by providing research to support others in their collaborative efforts. This collaborative effort and new way of working manifests itself in a number of different ways. Firstly, the platform brings together, within the Department of Health Sciences at the Högskolan Kristianstad, a multidisciplinary team drawn from its different programme areas of public health, nursing and social care. Secondly, it has adopted as its core research philosophy the principles of action research whereby research is done with people rather than on people and key research questions and issues are identified in collaboration with professionals and citizens. Therefore, in addition to the collaboration between the Högskolan and Region Skåne at a strategic level, each of the research initiatives has led to the creation of many new partnerships between academia and the community. This has meant that the research undertaken by the platform is directly relevant to local needs, while at the same time integrating with the research expertise and interests of the staff involved. Finding common interests across a range of agendas, including dovetailing into research issues that form the focus of the wider international research community, are central issues in academic – community engagement. The research initiatives outlined in this report are a product of that engagement and are intended to ensure the creation of local knowledge for practice development as well as more generalized scientific knowledge for the research community.

2.2 Building the infrastructure

New partnerships and new ways of working create new challenges and tensions, many of which are well documented in the research literature (Hornby and Atkins 2000). Effective collaboration does not just happen but is built on mutual trust and respect and requires investment (Schrum, et al 2001). The adoption of a central research philosophy unconnected to any individual discipline has been the mechanism by which it has been achieved in this case.

During the early months of the platform's existence effort was focused on creating a common philosophy and building a research team within the Högskolan. This team collectively contributed to the development of the platform's aims and objectives, its core philosophy and approach. (Appendix 1) While action research is well developed in the area of working life, social care and educational research in Sweden, it is less well developed academically within the area of health care (Hansson, A 2003). Staff development in the approaches and methodology of action research was supported by a guest professor from the UK, where action research has been developed extensively in this field (Waterman et al, 2001). One of the key challenges for academic staff has been to move away from the notion of the individual researcher following his/her own research interests to one of working within a team where the focus of the research comes from the community. For those with whom we have been working, the challenge has been to integrate the research process into daily patterns of work and to find the time to be more actively engaged in research decision-making. For the academic community there has been the challenge of matching the academic demands of postgraduate education and the need for staff to publish with the need for immediate research results to inform action within health care practice, as well as the political demand for results from investment in research. These tensions have been found in similar initiatives throughout the world (Loan- Clarke and Preston, 2002). Experience demonstrates, however, that through mutual understanding such issues can be worked through.

They also become easier to negotiate if sufficient resources are put into the process of building relationships in the early stages and working through areas of conflict as time progresses.

2.3 Research Approach and philosophical underpinnings

Central to the platform's approach to research is the methodology of action-research. The philosophical underpinning for this approach is critical realism which grew in response to the limitations of previously dominant research paradigms such as positivism and interpretism, chiefly associated with quantitative and qualitative methods respectively (Winter and Mumm-Giddings, 2001). Action research is being used increasingly worldwide as a way of bridging the divide that exists between the findings of new research, including the development of new theories, and their implementation in practice (Meyer, 2003). As an approach it is more inclusive in terms of the type of knowledge developed since it incorporates practice knowledge and lay knowledge as well as expert knowledge. In traditional approaches to research, research is done by experts, and some time later it is expected to be implemented in practice. In contrast action research is about practice centred and patient centred research.

Practitioner centred research taps into practical expertise, recognizing that practitioners develop tacit knowledge based on experience which enables them to decide whether or not it is appropriate to adopt scientific evidence in an individual case (Rolfe, 1998). This practitioner knowledge is also important in the situations of uncertainty, instability and value conflict that exist in the real world away from the laboratory. It also ensures that the implementation of findings generated in a hospital setting (where most clinical research is done) are not inappropriately implemented in a different setting, such as primary care or a care home, where the context is very different. Patient centred research similarly taps into the idea of the patient as an active participant in their own care through inclusion of their perspective or knowledge of their own body and illness. Such notions are contained in the concept of the expert patient (Agency for Health Care Research, 2002; Tang and Anderson, 1999). Action research represents a progressive mode of research with an emphasis on reflexivity and trans-disciplinarity as advocated by Gibbons et al (1994) in their book on research and development in science and technology. As such it is ideally suited as a research approach to support local health system development.

A distinctive feature of action research is the way that research work is done. The process encourages a greater integration between research and the development of practice through a series of cycles (Figure 1a, 1b).

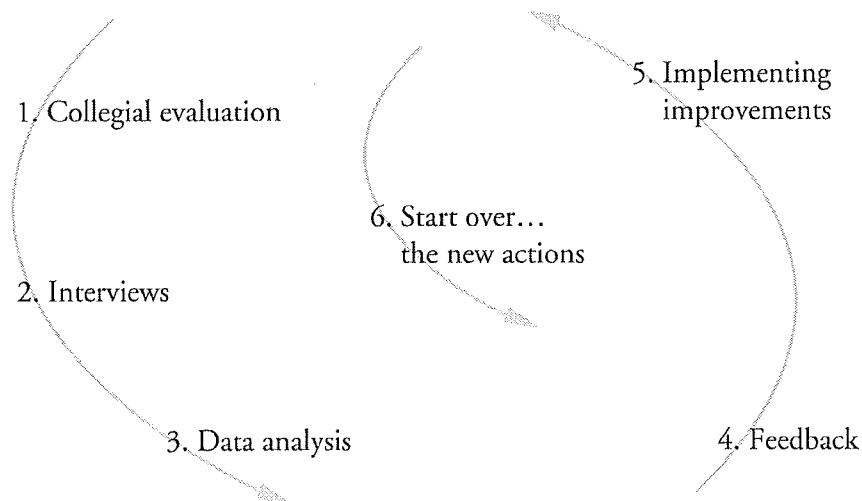


Figure 1a. Model illustrating a series of activity cycles during the working process of action research (Dychawy-Rosner, 2004).

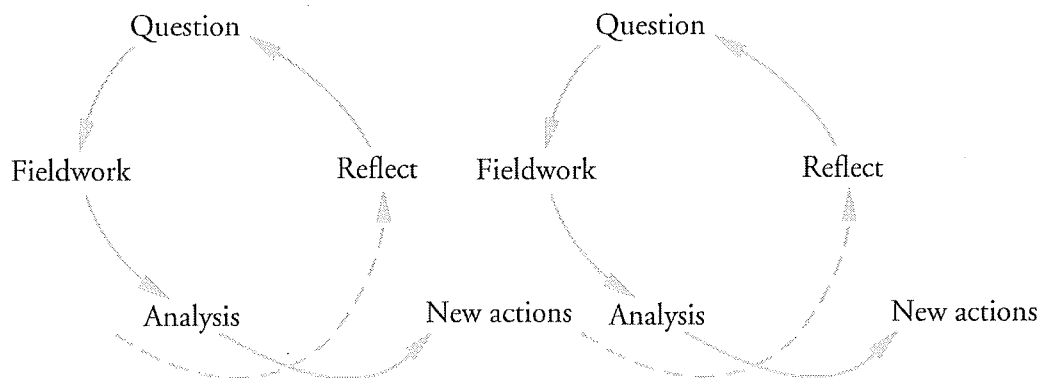


Figure 1b. Cyclical Research Process (Wadsworth, 1998).

The way that the research process is undertaken is as important as the outcome in the development of research knowledge. In essence it puts the development back into research and development. In many ways it is a process that is similar to clinical audit or quality assurance. It constitutes a systematic inquiry process, which uses appropriate conventional research methods depending on the research question. The research question itself has been generated from a real world practical issue.

A key element in the process is the feeding back of the results of any data collection and analysis to the co-researchers who are working in the practice context, to encourage reflection and possible changes in courses of action or generation of new ones and their evaluation. It is the intention of the research team, where possible and in keeping with its agreed philosophy

(Appendix 1), to encourage maximum participation in the research process. This takes time but there is now a strong evidence base that such an approach not only generates more timely research knowledge in the long run but also greater ownership of the results of any evaluation or research (Springett, 2001).

Because of the close interlocking of research and practice, the pace of development of research varies between projects depending on local circumstances, in order to be responsive and sensitive to local needs. In some cases local circumstances have been such that it has not been possible to develop a consensus on key research questions immediately and time has been required to build relationships, or in some cases the absence of basic research in defining the extent of a problem has had to be undertaken. . In some initiatives the issues such as professional power and identity, which act as barrier to närsjukvård also act as a barrier to collaborative action research. (Ekman Phillips et al 2003; Vernon et al, 2003, Sloper, 2004). As a result of these different factors the projects reported in part 2 of this report are at different stages of development but all are following the same cyclical process that is a key feature of action research (Stringer and Genat, 2004).

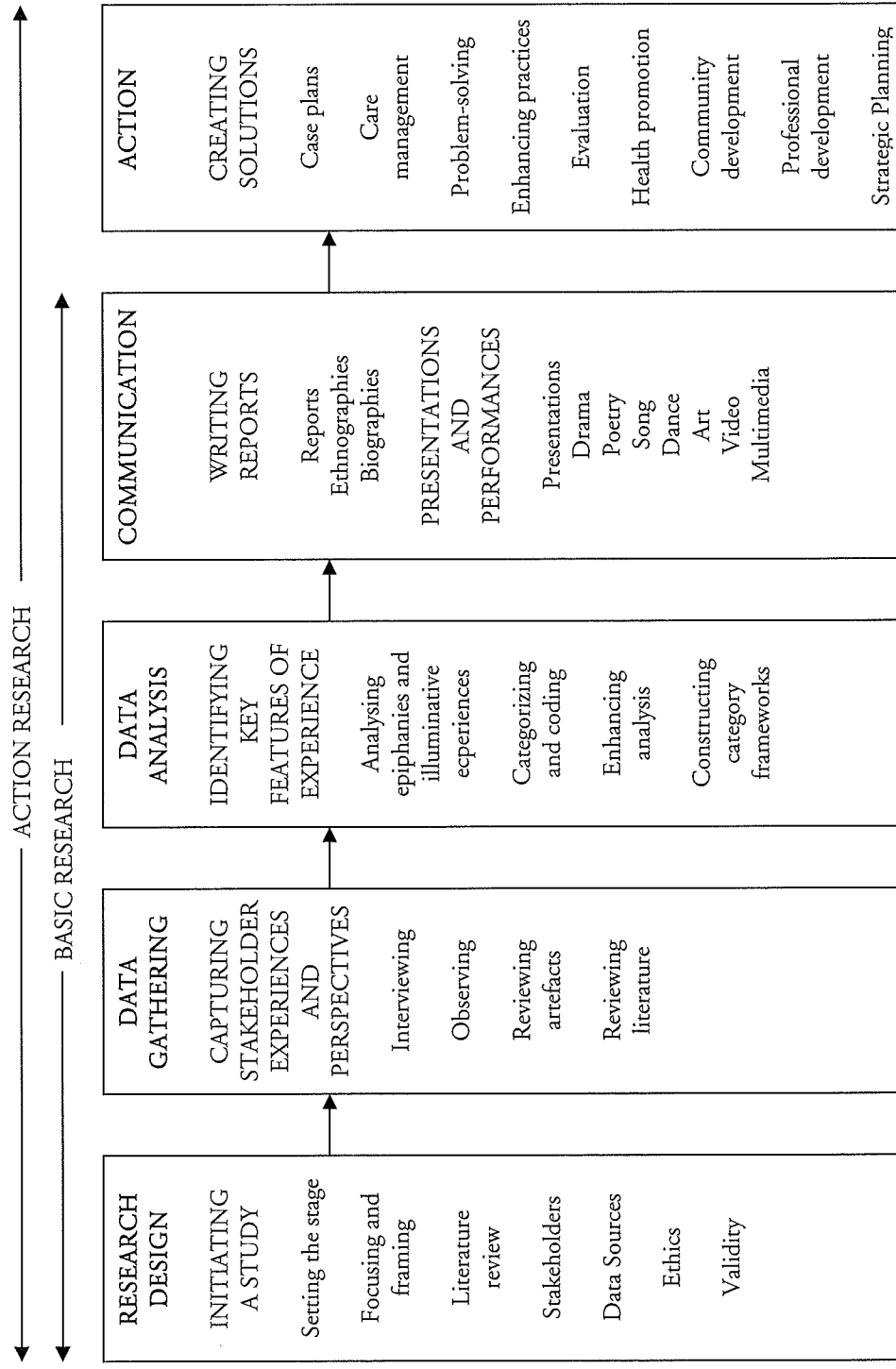


Figure 2. Action Research Sequence (Stringer & Genat, 2004)

2.4 Scope of Research within the Närsjukvård theme

The vision underpinning Skånsk Livskraft's notion of Närsjukvård in terms of the health care system is wide ranging. A documentary analysis has been undertaken of the key policy documents, the research literature and other material relating to the concept. This together with the initial requests for research support in relation to specific initiatives which came directly from members of the original steering group and a skills audit of staff within the Höskolan, who had expressed an interest in being involved in the platform, has influenced the overarching themes that form the chosen focus of the research platform this year.

- The process of collaboration and health system change
- Patients experience of, and participation in decision making, concerning their health care
- Prevention and health promotion

Consistent with local policy requirements, current research initiatives cross the spectrum of **elderly people with multiple illnesses, those with chronic diseases, children and their families, and people with mental illnesses**. They also start from the different vantage points of primary care, commune and hospital, within the health care system. In an attempt to take a more holistic perspective, it is not the intention at the moment for the work of the platform to be focused particularly on the clinical aspects of any one specific disease or illness. In the many documents that underpin Närsjukvård, overwhelming emphasis is placed on the needs of the patient being at the centre of care and that patient near research (Region Skåne, 2003) should support this. This platform hopes to fulfil this remit, both by viewing the patient as a whole person and directly involving citizens and patients in the research process.

Research has demonstrated that there is a tension between patient perceptions of the importance of care outcomes such as easy access, geographical proximity and friendly doctors and nurses and the focus of clinical staff on "objective" medical effectiveness of a particular treatment. Different professional groups also interpret what patient centred care means in different ways (Gillespie et al 2004; Mead and Bower, 2000). Understanding these differences in the context of Närsjukvård in north east Skåne will contribute to the development of new ways of working.

Table 1 shows the relationship between the specific research initiatives, the research themes the "entry point" into the system for the researchers and the sectors currently involved.

Each research initiative also has its own specific research focus, which has generated specific research questions depending on local requirements. These are shown in Table 2. In terms of methodology, mainly qualitative methods are currently being used. However, the intention is to adopt a multi-method approach overall, depending on the research questions being asked. Most research projects are either undertaking or have undertaken some data collection to identify key contextual factors and provide a baseline against which to measure the changes taking place in relation to the health care system, care process or practice development, depending on the focus.

2.4.1 Table 1. The relationship between the specific research initiatives

Initiative	<u>Research Theme</u>			<u>Initial entry point</u>				<u>Sectors involved</u>				
	Patient Perspective	Prevention and Health promotion	Collaboration between care professionals	Community Care	Primary Care	Hospital	Other*	Private	Community & social care	Voluntary sector	Region Hospital	Region Primary care
Focus												
HOP Närsjukvård implementation pilot												
Family health Care in Näsby												
Community Care in Bromölla												
FoU clinical network												
Fenix												
Psychiatric care												

*includes private citizens, businesses, patient associations etc.

2.4.2 Table 2. Specific research focus which has generated specific research questions for initiatives

	Initiative	Key research aims and objectives	Current Research question
Näsby Family care	Family health Care in Näsby	<ul style="list-style-type: none"> To examine the development of a Family centre from the families' perspective. 	<ul style="list-style-type: none"> What are the assumptions and expectations on the Family house from the professionals' perspective? What are the assumptions and expectations on the Family house from the families' perspective? How have the families been involved in the development of the Family house? To what extent does the service offered by the Family House meet the needs of its target population?
	Näsby primary care centre, HBS	<ul style="list-style-type: none"> To identify the needs of local women of Kurdish, Arabic and former Yugoslavian background who have not completed a Swedish for foreigners course or had an assigned traineeship. To use this information to develop and evaluate an action strategy within the primary care centre and in collaboration with other agencies within Näsby 	<ul style="list-style-type: none"> What are the daily living experiences of this group within the community and how do those experiences impact on their health and influence their utilisation of the primary health service How can their needs be addressed effectively?
The Närsjukvård pilot implementation project in the municipalities of Hålsjöholm, Osby, Perstorp	Evaluation of Hålsjöholm/Osby/Perstorp initiative organisational change with particular reference to heart failure patients and their voice	<ul style="list-style-type: none"> To examine how organisational change in health care is structurally connected to other processes and especially to the presence/absence of <i>the patients voice</i>. To study how the implementation process is affected by how people translate the ideas of Skånsk Livskraft into practice. 	<ol style="list-style-type: none"> What meaning does Near Sick Care (Närsjukvård) carry for patients, relatives and citizens that have personal experience (or not) from health care facilities? Which experiences of health care (sjukvård) and ideas about Near Sick Care (Närsjukvård) in terms of content and organisation do patients, relatives and citizens have?/Which experiences and ideas about social (municipality) care and community care do patients, relatives and citizens have? How and what do professionals learn in the context of Near Sick Care (Närsjukvård) as a pilot project? How do voluntary organisations and the Health Care District cooperate in "after care" (care after leaving the hospital)? What views on means of supporting enhanced life quality can be asserted through talks with persons active in voluntary organisations with members that have experienced or are experiencing difficulties in daily life due to illness/disease?
	Närsjukvård organisational changes around wound care	<ul style="list-style-type: none"> To provide insights into organisational change, the development of the nearby care. An evaluation of the impact of the changes, in the way of working with wound care, on the staff and personnel. 	<ul style="list-style-type: none"> How are the visions and concepts of value about nearby care, formulated by Skånsk livskraft, understood and translated into practice by the staff and personnel at different levels within the health care organisation? Where do the ideas, knowledge and decisions to the changes of the wound care come from (Lipsky 1990)? How are the changes communicated between different levels, groups and individuals within the organisation? How is the changes understood and experienced? How do the staff and personnel perceive the wound care, the ways of working, and the needs of the patients? How does the cooperation work between different institutions, levels and professionals, as well as ordinary personnel and patients?
	Wound Care process - how patients experience the leg ulcer care	<ul style="list-style-type: none"> An evaluation of the impact of changes in the health care process on the patient experience of their care with particular reference to leg ulcers 	<ul style="list-style-type: none"> What is the patient's experience of their care and what impact have changes in practice had on that experience?
	Care Processes, patients with chronic illnesses.	<ul style="list-style-type: none"> To investigate how patients with chronic illnesses understand their illness and to what extent they participate in their own care. To examine the impact this understanding has on the professional's behaviour. 	<ul style="list-style-type: none"> How do patients understand their illness? How do the patients act according to their understanding of their illness? To what extent is the decision making and actions with regard to care a participatory process.

Psychiatry	Psychiatry	<ul style="list-style-type: none"> Part 1 To examine how language influences collaboration between the municipality and the child- and adult psychiatry . Part 2 examine the prerequisites for the establishment of Närsjukvård in the context of psychiatry particularly with respect to outpatient support. 	<p>The research question in the first part of project is:</p> <ul style="list-style-type: none"> How is the linguistic construction of boundaries happening in collaboration processes? <p>For part 2</p> <ul style="list-style-type: none"> What experiences do the patients/clients/parents/relatives of the treatment and the rehabilitation? Are there any health promoting elements in the treatment and the rehabilitation? What is less good/bad? How do the patients/clients/parents/relatives want the treatment/rehabilitation to be designed?
FoU clinical networks	FoU clinical network	<ul style="list-style-type: none"> To find out how development, learning and change take place within the R&D Networks and ascertain how the aims of the networks are being translated into practice. To examine which elements, conditions and ways of working that have an influence on changes taking place, in order to develop a model for good practice. 	<ul style="list-style-type: none"> Which development and changes are taking place within the R&D networks? Which elements, conditions and ways of working have an influence on the changes taking place? How and in what way does learning take place? To what extent does the work of the R&D networks have an impact on the health care system in the northeast of Skåne? How can the conditions for learning connected with the work accomplished within the networks be improved?
Fenix	Fenix	<ul style="list-style-type: none"> To provide research support to develop ways of gaining access to persons treated for cancer and their relatives who need psychosocial support to develop alternative forms for support individual or as group activities. 	<ul style="list-style-type: none"> How can collaboration between in hospital care and primary care for patients treated for cancer and their family be improved? What are relatives' expectations and how are their needs for psychosocial support were met and how they experienced the professional care provided?
Bromölla Municipality care	Municipality based home care	<ul style="list-style-type: none"> To evaluate new approaches to care in community nursing using collaborative inquiry To explore the impact of new integrated care management process using multiprofessional teams. 	<ul style="list-style-type: none"> What is the impact of the supervision process on community nursing practice How does that impact on the way care is delivered ? What are the key issues that community nurses face in their current practice? What is the nature of the networks that are required to deliver care to multiple chronically sick people in the community and how do the different professionals relate to each other in the delivery of care. How can an integrated multiprofessional care management process deliver client centred care. What is the impact of an action research process on the development of new ways of approaching care.
	Patient' opportunities for self-care	<ul style="list-style-type: none"> To examine patient education in primary care, municipality care and specialized care. To examine the impact of improvements in patient education on self care. 	<ul style="list-style-type: none"> How do health professionals perceive their practice concerning patient education and self-care? What are the experiences of patients concerning patient education and self-care? How can patient education be developed to improve self-care?

2.5 Connecting with other researchers

The research platform, of course, is not the only player in the research and development process underpinning the development of Närsjukvård in north east Skåne. There are many other researchers, both within the Högskolan and elsewhere in the Region and in Sweden as a whole, who are undertaking research in this area. Where possible, we are linking with these other researchers so as to ensure our work complements what is already being done by others. This takes a number of forms. In the evaluation of the Närsjukvård initiative based in Hässleholm we are focusing on areas consistent with the focus of the platform, that are not covered by the other researchers from Stockholm and Skåne FoU Kommunförbundet. We are encouraging links between clinical researchers within the Högskolan with clinical researchers within the care setting, for example, through the FoU network. In other cases we are linking with key knowledge centres such as the one being developed by Professor Lindholm on Wound Care. Nursing, social work and public health masters students undertaking dissertations have also become involved in research projects in the area of Närsjukvård. Doctoral students undertaking research at other universities have undertaken work that has connected with our own. An example is the research on collaborative working in the psychiatric sector, which forms one of the research reports presented here. We are also linking with researchers further a field through attendance at research conferences, participation in action research networks and having invited guest speakers at our regular research seminars (Appendix 2). Looking ahead we are currently collaborating with Skåne FoU Kommunförbundet on a national conference in November 2005, and with the north east Region FoU on a local conference in April 2005.

2.6 Research Outputs

A range of research outputs have been produced, or are currently under production as described in the individual reports contained in part 2. Firstly there are the local reports and feedback workshops with members of the individual research initiatives. Some of these have already taken place. Secondly, a number of papers for submission to key academic journals are planned; some specific to the individual research initiatives but some will be focusing on some cross cutting issues. Of these latter papers the first will focus on the concept of Närsjukvård and how it is understood by health professionals working in different parts of the health care system in north eastern Skåne. Another will review solutions to the need for integrated care provision in other parts of Europe. Thirdly the platform will be producing its own set of research publications. The planned publications will help build a track record in research that will provide the necessary base for attracting national and international research funding.

Three full-time and two part time doctoral students are currently attached to the work of the platform. Each has produced or is producing a project plan for their doctoral studies. One student is already registered with an English university for her doctoral studies and agreement has been reached with Örebro University to develop a partnership arrangement for the doctoral studies of the remaining and future students. Supervision will be shared between supervisors at the Universities concerned and senior staff within the platform.

2.7 Future Research Plans

At the moment the entry point for the researchers into the local health care system has been through contacts with health care professionals and currently it is the latter's perspective that provides the lens through which care and system change is viewed. It is hoped to extend our focus on the citizen and the patient perspective through greater active service user involvement in the research process and through taking other entry points into the health care system, for example from the point of view of a specific geographical community or patient/user group. Capacity to meet the local demand for research will also depend on the acquisition of additional research resources including staff. Applying for research money to fund specific research initiatives and supplement core funding will provide an additional focus of the platforms work. Discussions are currently under way with Professor Lindholm, for example to develop a joint research bid in the area of wound care. Meanwhile, further linkages between specific expert knowledge centres and with education programmes within the Högskolan will be consolidated.

Some of the research that will be developed next year are linked to preliminary research undertaken this year. For example, during this year a survey was undertaken of young people in Kristianstad by the platform for the municipality. The survey forms part of a national survey. It included a particular question inserted by the Platform on health care access and use. Data from this survey will form the basis of the development of research with Kristianstad commune in the area of health promotion and access to health care for young people. Other research that has only just begun, for example in psychiatric care, will be continued, while research linked to existing research initiatives will be consolidated.

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3. Part Two

Individual Initiatives

3.1 Family health in Näsby

3.1.1 The Family house in Näsby – a primary care based collaboration project aiming to promote children's and parents' health in the surrounding community

3.1.2 Näsby Primary Care Centre, HBS (Humana Basala Strategier) – a project around finding ways to meet the varying needs of immigrants seeking support from the local care centre

3.1.1 The Family house in Näsby

Cecilia Lindskov

3.1.1 The Family house in Näsby

- Lead researchers: Cecilia Lindskov
- Co researchers: Leif Karlsson, Agneta Abrahamsson and Jane Springett

Originating Agent

Lars Åke Johansson, former head of primary care, and the Family House steering group

Reference Group

Staff at the family house, a steering group that consists of managers from the municipality and the regional authorities, various heads of departments; the head of social welfare for children, the headmaster of the nursery school, the head of the health centre in Näsby and the public health officer from the region

Introduction and rationale

To promote health and well-being, foremost among children and their parents, coalitions between medical and social contributions are developing in Sweden. These coalitions are called Family centres and mostly consist of different professionals working together located under the same roof in the local community. The basis of the work is mother health care, children health care, childcare centre and social services, which fulfils the definition of a Family centre that The National Institute of Public Health in Sweden requires. The family centre is a new family support system that is intended to improve the present system. There is a wish for the Family centre to meet the needs of a family with small children by promoting their health and their own resources, to prevent problems instead of helping when there already is damage, and try to use the resources better through collaboration taking a holistic view of the family (Bak & Gunnarsson, 2000).

This is intended to be achieved by providing:

- A place where children and parents can meet
- Strengthening the social network around the child and the parents
- Finding ways to encourage the participation of the families in the work of the family house
- Being a knowledge- and information centre
- Giving easily available support
- Giving all round service through collaboration between different professionals and other authorities

(Folkhälsoinstitutet, 2000:10)

The Family house in Näsby started in the spring of 2004 and is a financial cooperation between the regional authorities and the municipality. It lies in an area of the municipality called Näsby, which consists of Gamlegården and Gamla Näsby. The major part Gamlegården where the

Family house is situated is described as an area with higher unemployment, higher social welfare allowances and higher levels of immigrants than the municipality as a whole (Familjehus på Näsby Kristianstads kommun, 2000).

The target group is mostly families with small children between 0-6 years. The multi-disciplinary team consists of 2 midwives, 3 paediatric nurses, 1 nursery school teacher, 1 social worker without authoritative position, 1 psychologist and 1 nurse assistant. The Family house has support of a steering group that consists of managers from the municipality and the regional authorities. It also includes various heads of departments; the head of social welfare for children, the headmaster of the nursery school, the head of the health centre in Näsby and the public health officer from the region. The common vision is to promote health and fellowship in the local community by working with the needs of families and individual family members taking their perspective as a starting point. It is hoped that people from different cultures, backgrounds and ages can get to know each other and thereby create their own social network (Verksamhetsplan Kristianstads kommun, 2002).

At an early stage of the development process the project group of the Family house, encouraged by the head of primary care who at the time was on the coordinating committee of the platform, contacted the Platform for research- and evaluation support. A multi disciplinary research team was formed to support and promote the development of the Family house. The cooperation increased during spring 2004 with several meetings with staff and steering group and project leader. The Research team presented the key issues in Participatory Action Research (PAR) and key stakeholders were identified: Families, staff, steering group and other key persons. The research is based on the methodological approaches where organisations, staff and users through dialogue, participation and influence and take an active part in creating knowledge and undertaking research.

There are a number of other research projects focusing on the area of Gamlegården/Näsby. It is likely that in the future these projects will be linked together in some way.

Key research aims and objectives

The overall aim of the research is to examine the development of the Family centre focusing on the families' perspective.

The main research questions are:

- What are the assumptions and expectations on the Family house from the professionals' perspective?
- What are the assumptions and expectations on the Family house from the families' perspective?
- How have the families been involved in the development of the Family house?
- To what extent does the service offered by the Family House meet the needs of its target population?

Current research question:

- What are the assumptions and expectations on the Family house from the families' perspective?

Theoretical perspectives

The original documents and previous evaluations of family centres are inspired by aspects of health promotion and social work; community development/empowerment, salutogenesis, social networks and a holistic view (Folkhälsoinstitutet, 2000:10; Verksamhetsplan Kristianstads Kommun, 2002; Bak & Gunnarsson, et al 2000).

Urie Bronfenbrenner (1979) offers a theoretical model in human development that provides a tool for understanding children's and families' situation in society from a holistic perspective. The ecological environment is conceived as a set of nested structures, each inside the next. The innermost level is the immediate setting containing the developing child and the family. This innermost level is called the micro-system. The next level is the meso-system. It consists of the connections between children's immediate settings and surroundings. It encompasses connections between micro-systems such as school, neighbourhood, and childcare centre. The exo-system surrounds the meso-system and refers to social settings that affect the child but do not include the child, such as the health services, parent's workplace, and institutions. Macro-systems consist of things that influence and sometimes support the child within the environment such as culture, norms and laws.

The three-dimensioned theory by Gerald Caplan has had a great impact on the development of prevention work in many areas other than psychology, where it was originally developed. He distinguishes three levels of prevention work. The first level is called "primary prevention" and it contains strategies that prevent psychological illness. It is a community concept and seeks to reduce the risk for a whole population. The secondary prevention strives to reduce the number of established cases of disorder in the population at risk. The tertiary prevention aims to reduce the rate in a community of defective functioning due to mental disorder. (Caplan, 1964). Prevention work in Family centres is mostly concentrated on the first and second level.

Like a lot of Family centres in Sweden the Family House in Kristianstad is situated in an area in the community with a high population of immigrant families. Immigrant dimension is therefore an important aspect. Minuchin (1996) writes that issues such as minority status are critical determining factors in family problems. According to him there are multiple elements in an ethnic group standing on a tripod of three cultures. There can be cultural elements traced to the origin country, those that are a part of the dominant culture, and finally the adaptation that foreigners have to make to racism in the dominant culture. These multiple demands may strengthen identity but can also lead to confusion of values and roles and to a sense of powerlessness in the face of the cultural complexity. Samarasinghe and Arvidsson (2002) have explored the impact of involuntary migration on the family health in order to identify specific health care issues related to refugee families in transition living in Sweden by interviewing members of 10 different families. They found that stressors like seeking asylum, changed roles and unemployment affected the families and that a friendly understanding attitude from the host country was the main factor in promoting health of the refugee families. Positive attitudes strengthen the coherence and emotional stability of the family system. Negative attitudes created psychological and physical health problems.

Community development is a model of working which aims to empower groups of people by identifying their concerns and working together with them. In that way new knowledge develops and people are offered possibilities for taking control over their lives. (Naidoo & Wills, 2000).

Empowerment increase self-esteems and personal control (Raeburn & Rootman, 1998; Forsberg & Starrin, 1997).

Aaron Antonovsky (1987) has coined the theory of salutogenesis in his aim to understand what keeps people healthy. His theory of how mental resources can promote health nowadays offers a general frame of reference for studies of health. The approach to salutogenesis is opposed to the usual approach of pathogenesis. Social networks are another important aspect of Family centres. According to Dalgard (1992) social networks are the informal relations between people collaborating more or less regularly with each other. A social network is something positive if it offers an individual social support but can also be negative if it contains problematic relations. Research shows that supportive social networks are important for health and well-being (SOU 1998:43).

Research process and outputs

The interview study

In the spring of 2004 an interview study was carried out as a first step in obtaining a base line in the research process. The purpose of the study was to capture different expectations and assumptions about the Family house during its early stages. Staff, steering group and some key persons were interviewed. The study covers 19 interviews. Three areas emerged as of key importance Expectations, cooperation and prevention work.

The variety of expectations as to the role if the family house held by the interviewees can be represented by four metaphors:

- *"The Reception"* which consists of the different activities (mother healthcare, child health care, nursery school and social services). The families get easily available support under the same roof.
- *"The Meeting place"* which offers the opportunity for the families to get to know each other without any pretensions.
- *"The Activity centre"* which has various activities that are not steered by the staff and includes involvement of different associations in the area.
- *"Peoples' house"* which are characterized by the notion of availability for everyone: Swedes/foreigners, men/women, young/old. The activity is not steered by the professionals. Instead it is the needs of families that are the guiding light in the work.

The internal collaboration and prevention work are described as very important ingredients in the Family house. Prevention work is the general efforts given by the mother health care, child health care, nursery school and the social services. By offering a meeting place and various group activities families have an opportunity to widen their social network, which is an important starting point of prevention work. The emphasis of the work is to promote and strengthen the resources of the families, not to treat their problems.

Workshops 2004

During two occasions in autumn –04 the staff, leaders of the various authorities and key persons have met together with the research team from the Platform. The purpose has been to develop relevant research questions. The analysis of the interview study was used as a starting point of the work and three areas of concern were drawn up by the first meeting:

- *Inside activity:* The participants wanted to develop the internal collaboration between the different professionals. One way of developing collaboration is to share a common vision of the Family house.
- *Outside activity:* Integration and participation of families is the core issue of the outside activity. The needs of families have to come in first hand.
- *Prevention work:* The concept of prevention work ought to be clarified and explored.

Next step, by the second workshop the participants answered three questions connected to the three research areas. The discussions were summarised in writing and verbally.

Question 1: Is it possible to have a common view, shared by all the professionals; is it necessary to develop the Family house and if, why?

The participants do not think it is necessary having a common view, on the contrary they emphasise that different visions can enrich the Family house.

Question 2: What does it mean to involve the families in the Family house and what does integration mean?

Involvement of families is created by having a start from the families' needs and perspectives. Integration is created in the meeting between old/young, foreigners/Swedes and leads to the creation of new networks outside the Family house.

Question 3: What is prevention work? What problems shall be prevented and who are the target groups?

The target groups are all the families in the area. The participants do not want to have a problem orientated perspective; instead they want to start from the families' expressed needs. Prevention work is a lot about helping people to develop social network/support.

From words to action – How will you concretize the issues that have appeared during the discussion of the (above) three questions?

- (1) It is important to have regular professional meetings, common supervision and to work across formal boundaries. In that way staff gets opportunities to learn to know each other and to take advantage of the different professional competences and perspectives.
- (2) Participation is created by the staff asking and having a sensitive ear about the needs of the families, but it can also be complemented by surveys and interviews.
- (3) Prevention work arises in the individual conversations and in the group activities in the Family house. Early contributions are an important concept and are defined as acting early to prevent a problematical development. Cooperation with other family supportive actors is also an important issue in prevention work

The role of the research team was also discussed in small groups from the following questions: **What kind of help do you want from the research team? What research area is the most important? What do we need to start with?**

The following wishes were declared from the groups:

- A summary in writing of the analysis of the interviews and the work during the workshops
- Long-term evaluation how the aims and objectives are followed
- Examination of the expectations and assumptions of the Family house from the families' perspective
- Developing the internal collaboration

Current plans

The research team has had one meeting in November -04 to plan the further research on the basis of the workshops. The staff of the Family house was given a summary in writing of the analysis of the interview study and of the work during the workshops.

The participants expressed that they wanted help to develop the work inside considering the collaboration, but also outside considering the relationship to the families. Reflections.

The collaboration seems to be something self-evident and the staff has already developed new ways of collaboration. This experience is shared by Bak & Gunnarsson (2000) in an evaluation of a Family centre in Gothenburg. They say that the collected location of professionals from different authorities working with the same families set aside a lot of obstacles of collaboration. The work of the Family house has the starting point from the families' perspectives with integration, participation and development of social network as important aspects which also can be related to the essentially ideas of community development. (Ronnby, 1991).

The work inside the Family house is developing favourable and they are already working across formal boundaries. The work outside the Family house has the ambition to try to take the families' needs seriously and to develop the activities from the families' perspectives. The evaluation and research ought to concentrate on the families' situation and conditions and interests.

The first step of the research- and evaluation process in spring -05 will be an examination of the families' assumptions and expectations of the Family house. To develop the inside work the staff individually will write diaries about the collaboration. In January a new workshop is planned with the staff of the Family house.

The research will probably distinguish between 3 cycles. The first cycle during 2004 was a baseline examining different assumptions and expectations of the Family house from the professionals' perspective. Cycle 2 and 3 are connected to the research questions developed from the cooperation with the participants during the workshops. Three articles are planned connected to the three cycles. The first article will be written and hopefully published during 2005.

Cycle one, year 2004: What are the assumptions and expectations on the Family house in Näsby from the professionals' perspective?

Phase 1, first data collection: To be able to understand the developing process of the Family house an interview study has been done to explore different assumptions/perspectives of the staff and steering group (totally 19 persons).

Phase 2, feedback: Key stakeholders and researcher have met in Workshops to have a dialogue about the findings. Key stakeholders will together with the researcher define new issues to investigate.

Phase 3, planning: Planning for new data collection together with the staff. This planning have been carried out during a Workshop in late autumn -04

Cycle two, year 2005: What are the assumptions and expectations on the Family house from the families' perspective?

Phase 1, second data collection: Interviews with families to explore different assumptions and perspectives about the Family house and its context and how they compare.

Phase 2, feedback: Stakeholders and researchers will meet in Workshops to have a dialogue about the findings. The analysed data from the data collections will lead to initiating actions that are relevant for the areas of concern. This planning for action will be done in Workshops with the different key stakeholders in late spring -05.

Cycle 3, year 2006-2007: How have the families been involved in the development of the Family house?

The research will continue to follow the interactive structure of the phases above. In cycle two and three the researcher and key stakeholders will focus on examining how the families have been involved in the development of the Family house.

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3.1.2 Näsby Primary Care Centre, HBS (Humana Basala Strategier), to work with other agencies in Näsby to help these local women so they have access to the right support in the right place

Agneta Abrahamsson

3.1.2 Näsby primary care centre, HBS (Humana Basala Strategier), to work with other agencies in Näsby to help these local women so they have access to the right support in the right place

- Lead researcher: Agneta Abrahamsson
- Co-researchers: Staff at the primary care centre and representatives from the community and voluntary organizations and associations

Originating Agent
Staff at the care centre

Reference Group
Representatives from the community associations, staff from the care centre, staff from Näsby family house, staff from the integration office, staff from Högskolan Kristianstad

Introduction and rationale

Näsby primary care centre serves an area with a large immigrant population. Over the last ten years many have looked to the health care centre as a solution to many different problems and this has been a cause of concern for the clinical staff. Women in particular are a source of concern as they are attending the primary care centre with many health problems. In cases where there is no medical problems the women express feelings of powerlessness and suffering and their continued accessing of the health centre causes frustration both for the staff and for the clients as it is perceived as an inappropriate utilisation of health care resources. The immigrant “problem” has been the source of considerable discussion within the centre. The impression gained is that the women feel isolated and the health care centre is their only point of contact. The aim therefore is to work with other agencies in Näsby to help these local women so they have access to the right support in the right place.

Key research aims and objectives

To identify the needs of local women of Kurdish, Arabic and former Yugoslavian background in the age range 20-45 who have not completed a Swedish for foreigners course or had an assigned traineeship.

To use this information to develop and evaluate an action strategy within the primary care centre and in collaboration with other agencies within Näsby.

Current Research Questions

- How do this target group see their situation?
- How do they experience their daily life?
- What solutions do they see to meeting their needs?

Research process

A reference group has been set up to guide the research and act as facilitators of the research and to ensure it is culturally sensitive. A literature review is taking place and the interview protocol is being developed. Individual interviews will take place from a sample group and this will be followed by focus groups. The information will be fed back to the participants from the interviews during the focus groups and then fed back to the reference group. This process has just started.

Future Plans

It is expected that this research will develop links locally with other projects and help to inform the family centre development.

3.2 The Närsjukvård pilot implementation project in the municipalities of Hässleholm, Osby, Perstorp

3.2.1 Evaluation of Hässleholm/Osby/Perstorp initiative organizational change with particular reference to heart failure patients

3.2.2 Närsjukvård changes in ways of working around wound care

3.2.3 Wound Care process – how patients experience leg ulcer care

3.2.4 Care Processes and patients with chronic illnesses

3.2.1 The Närsjukvård pilot implementation project in the municipalities of Hässleholm, Osby, Perstorp.

Evaluation of Hässleholm/Osby/Perstorp initiative organizational change with particular reference to heart failure patients and their voice

Sven-Erik Olsson

3.2.1 Evaluation of Hässleholm/Osby/Perstorp initiative organizational change with particular reference to heart failure patients and their voice

- Lead Researcher: Sven-Erik Olsson
- Co-researchers: Birgitta Höglund, Pia Petersson

Originating agent
CUU, HOP, Sviktkeðjan

Reference group
Hässleholm hospital organization – NSS, heart failure chain, CUU, Hässleholm, Osby, Perstorp

Introduction and rationale

The research has several origins. The first part was developed in collaboration with CUU (Roger Nihlén and Eva Theander). The studies on HOP Steering Group and the Heartfailure Chain/Review Sessions have been developed in cooperation with Eva Theander, Ingrid Vesterberg and Roger Nihlén. The studies on the Patients Voice have emerged from a combination of the basic aims of the Research Platform, an emphasis on the patients' perspectives and experiences and what has emerged from initial observations at the CUU.

The research site is the geographically and organisationally concentrated in the areas of Hässleholm, Osby and Perstorp. The Hospital Organization of Hässleholm (Hässleholms Sjukhusorganisation) has become a central point of reference, since it has been designated as a pilot project for the development of Närsjukvård. This report deals mainly with the research work conducted by Sven-Erik Olsson, one of four researchers working mainly in the Hässleholm-Osby-Perstorp area. The others are Birgitta Höglund, Ingela Olsson and Pia Petersson. Birgitta Höglund and Pia Petersson are attached to the network on *Wounds*, exploring different aspects of patients and professional experiences. Ingela Olsson is planning a research project in collaboration with the CUU-ward (Center for Education and Development) at the hospital in Hässleholm. The team meets regularly and a pooling of results is planned as part of the overall evaluation of the Hospital Organisation of Hässleholm as a pilot project within Skånsk Livskraft. Other researchers are involved in the HOP initiative and the research team has made sure it complements the other research taking place.

Key research aims and objectives

The key research aim is to study how organizational change in health care is structurally connected to other processes and especially to the presence/absence of *the patient's voice*. The Hässleholm Hospital Organisation (Hässleholms Sjukhusorganisation) occupies an ideologically strategic point of reference as a *designated pilot project* in the overall program of Närsjukvård within Skånsk Livskraft – Vård och hälsa (Hälsö- och sjukvårdsledningen 2004).

Among the objectives is to study how the implementation process is affected by the inclusive and exclusive operations of translation (Lindberg 2002) that are an embedded part of communication and how the program Scania LifeForce – Care and health may be developed and enhanced through dialogue and participation (Ekman Philips, et al. 2003).

The investigations and cooperative processes entered by the researcher(s) will be guided by a search for presence/absence of *the patients voice*. The research process will inevitably be one that is characterised by constant reorganization and reevaluation due to its structural coupling to the dynamic processes of several systems (interaction systems, organization systems and society) and system levels. An overall objective will be to maintain focus on issues relating to the patients voice and identifying emerging arenas for data collecting/creation and cooperation.

The first objective was to connect to the actuality of Närsjukvård as hospital care at a ward. This connected with a wish expressed from the project manager of an educational and development ward (Centrum för Undervisning och Utveckling, CUU) at the Hässleholm hospital. It was agreed that the researcher should make observations at the ward and that feedback should follow in connection with a regular ward meeting. The purpose of the feedback was to provide for learning opportunities for the staff as well as the researcher. Observations were undertaken in the first half of 2004. During 2004 and 2005 the plan is to follow the cooperative efforts among professionals under the aegis of the HOP (Hässleholm-Osby-Perstorp) steering group and the Heart Failure Care Chain (Sviktkedjan). Another objective is to look for opportunities to talk directly with patients, relatives and citizens on the subject of care and support. The latter part is under development and is expected to more fully unfold in the first quarter of 2005 and then be further pursued.

The research is done within the context of action research (Ashcraft 2000; Lundberg and Starrin 2001) and systemic analysis and development (Dixon 1999; Selznick 1969; Weick 1995). A central objective is to look for opportunities for learning through dialogue and cooperative initiatives. It is projected that research will change the framework being researched and the framework being researched will change research in intertwining sequences (Shotter 2004).

Current Research Questions

The current research questions are:

- (6) What meaning does Near Sick Care (Närsjukvård) carry for patients, relatives and citizens that have personal experience (or not) from health care facilities?
- (7) Which experiences of health care (sjukvård) and ideas about Near Sick Care (Närsjukvård) in terms of content and organization do patients, relatives and citizens have?/Which experiences and ideas about social (municipality) care and community care do patients, relatives and citizens have?
- (8) How and what do professionals learn in the context of Near Sick Care (Närsjukvård) as a pilot project?
- (9) How do voluntary organizations and the Health Care District cooperate in "after care" (care after leaving the hospital)?
- (10) What views on means of supporting enhanced life quality can be asserted through talks with persons active in voluntary organizations with members that have experienced or are experiencing difficulties in daily life due to illness/disease?

It should be noted that in keeping with the aims of the research platform which gives value to all form of knowledge and aims to integrate those different types of knowledge, the answers to these

questions can emerge from a variety of sources including the dialogue sessions, review group meetings, researcher observations and interviews.

Theoretical perspectives

Research theories and knowledge that currently is intertwined with the research is mainly institutional (Olsson 1988; Selznick 1968; Selznick 1969), constructive (Roberts 2001; Searle 1997) and systemic/systems (Højlund and La Cour 2001; Houston 1999; Weick 1995) theories plus specific perspectives on organizational learning (Dixon 1999; Lindberg 2002; Payne 2000) and consulting (Moullin 2002; Weiss 2003). An extensive literature search has been made utilizing Elin@kristianstad, Sage Journals on Line and other databases. Keywords used have been combinations of the following words:

(1) Social, (2) Health, (3) Elderly, (4) Care, (5) Organisation/al, (6) Cooperation, (7) Learning, (8) Change, (9) System(ic), (10) Consulting, (11) Hospital, (12) Primary Care, (13) Community, (14) Changing, (15) Capacity, (16) Welfare, (17) Patient, (18) Need, (19) Service, (20) Teamwork

More than 500 articles and books have been judged as relevant and are kept in a register (EndNote) for further explorations.

Research process

The research encompasses four distinct strands: the CUU, the Heartfailure chain/Review sessions, the HOP steering Group and the Patients Voice. The description of the research process is divided along these four strands:

CUU

This part is described in brief above. The connection to the CUU has been reconstructed and realigned following the agreement between key persons involved in the CUU and in the Heartfailure Chain respectively agreeing upon a cooperative venture as of the third quarter 2004. How this will evolve and affect the research is currently evaluated/negotiated. A continuation of research of more specific internal processes at CUU is under development but will not be described here. It will be a part of a dissertation project by research platform participant and teacher Ingela Olsson, which is currently under discussion.

Heartfailure chain (Hjärtsvikt kedjan)

The plan is to follow the review sessions (genomlysningar) as an observer/participant observer. The sessions started in the second quarter of 2004 more or less in a trial form and a restart was made in October 2004. There is a planned schedule of sessions up until January 2005, which connects to a dialogue conference (seminar). It is assumed that the review sessions will continue, but the schedule is not set. The role of the researcher is negotiated at the beginning of each session and may vary.

The set goal of the review sessions is to achieve a cooperatively coordinated close care offering thereby creating an enhanced quality of life for the target group of patients with multiple sicknesses encompassing a significant element of heart failure. Using a specific methodology of case review ("genomlysning") of current patient cases it is assumed that patterns in the cooperation between primary care, municipalities and hospitals could be discovered. Four sessions are planned in the ongoing second phase ending in January 2005.

Participators in the review sessions include personnel working in direct care, in leadership positions and at strategic levels. They are employed in municipalities, primary care and hospitals.

The role of the researcher from the Research Platform participating in the sessions is to evaluate the process and outcomes from a patient perspective.

The review sessions are conducted by a senior staff member and follow a systemic model, the sixth points program that has been developed in conjunction with Jan Carlsson, a research and organizational development consultant working within the Hässleholm hospital organization. The sessions start with a setting of context including dividing the participators in groups according to functions (operational/strategic/support). Then (1) a narrator tells a story about a patient. In the next phase (2) questions may be directed to the narrator to enhance information richness. After that (3) a search for patterns is initiated followed by (4) making choices between different possibilities. An (5) action plan is suggested and the sessions is closed with (6) a receipt, when the narrator summons up and states if what has emerged has been helpful and in what way. The process is illustrated in figure 1 using Swedish language.

1. Berättelse = Story
2. Frågestund = Questions
3. Mönster = Patterns
4. Val = Choices
5. Handling = Action plan
6. Kvittens = Receipt

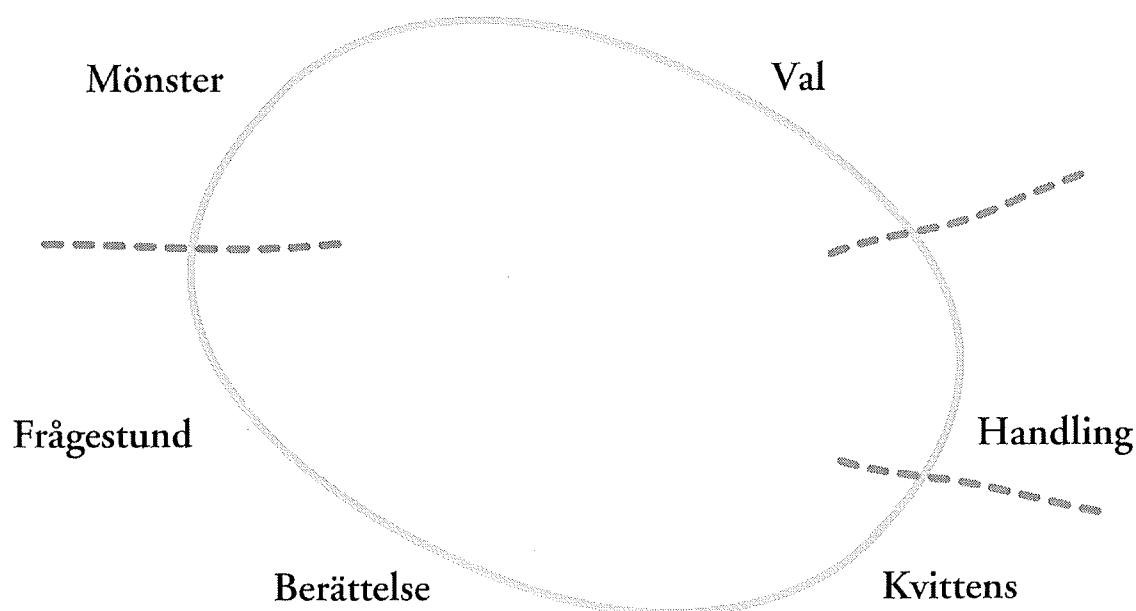


Figure 1. Sixth Point Program (Sexpunktprogrammet).

Dotted lines represent the imagined glass walls that are an essential part of the communicative context. The sixth point program emerges a modified implementation of *reflexive talks* (Andersen 2003) and *open talks* (Seikkula 2002). These communication frameworks originate in family therapy. Other implementators within the field of organization and change work include the Kensington Consulting Centre Foundation London GB, MacMann-Berg Århus DK and AMOVE AB Lund SE (Olsson 2004). The methodology is very similar to the story – dialogue

method used in another project on the research platform (3.6 Bromölla Municipality Care), which originated in the field of health promotion evaluation.

At the time of this report data collection is still in progress and draws on an ethnographic approach. Feedback is given when this has been agreed upon at the setting of context. Occasional spontaneous talks preceding sessions or after session may include feedback or further elaboration of intentions of participants. Data is collected in the form of *notes* by the researcher and collected protocols, agendas and documents that are talked about (when these are available). Individual patient data, such as journals are not part of data in the study of review sessions. Patients are not participating in the learning sessions. This is connected to a choice made by the professionals. The *consequentialities* in terms of structural limitations on the talks will be discussed in the analysis of events. Consequentialities are understood as non-causal contingents that are made available through observations.

HOP steering group and dialogue conferences

Another part of the research consists of following and participating in the meetings of the HOP steering group, dialogue conferences and other conferences. This makes it possible to follow how participants from the hospital, from primary care and from the municipalities look for and construct opportunities for cooperation and mutual learning. The observations have been affected by closure in connection with the intervention of other research/consultant work initiated by the association of regional and municipal authorities. The steering group accepted an offer to be researched/interviewed by a consultant and it has been announced that the subsequent feedback will be a closed session. The planned session of the steering group in November 2004 was cancelled.

The Patients Voice

This part of research is still in development with respect to the part involving *direct conversations/talks with* patients, relatives and citizens. It is an integrated part of the three strands described above in the sense that the researcher notices and appreciates how the Patients Voice is included/excluded by professionals.

Interviews and conversations were conducted during the observations at the ward (CUU). One interview has been made with a key member of a voluntary organization and documents describing the efforts of another voluntary organization has been collected. The interview is in transcription and the documents are being prepared for processing. Further interviews and conversations are planned to take place in 2005.

Outputs of the research process to date

To date "output" from the research process/researcher has been in the form of dialogues with participants/key persons, feedback and a progress report in Swedish.

The CUU observations were followed by a dialogue seminar with ward personnel in connection with a regular ward meeting. All staff got a report (for internal use only) with selected transcripts of notes made by the researcher. After reading the report they selected topics to discuss. This discussion took place in small groups. A summary reflection followed. The staff selected to focus on areas of improvement. These were connected with their goals to *listen to the patient* and to *ensure an acceptable level of privacy*. Events pictured in the report alerted the personnel to occasions where routinised goal-achievement conflicted with expressed wishes of the patient. These occasions were perceived by staff as *exceptions* and not as patterned behaviour. In the report there were also occasions where patients were *exposed*. Examples included not closing toilet-doors and discussions on patients taking place in open spaces, such as the corridor

and TV-room. Not closing the door was treated as an *exception* that could be amended by increasing awareness. The discussions held in open spaces were perceived as a more general issue, involving the lack of areas/rooms as well as routines such as the round system. Some events, such as relatives and patients expressing dissatisfaction with the restricted visiting hours, were constructed as *unmanageable* by the staff. There was the issue of *cohabitation*, with up to four patients in each room. Some patients requested privacy and or needed rest in a quiet environment. Extending visiting hours would conflict with these requests and needs. Also treatment was regularly performed in the ward. The scarcity of rooms for treatment and the routines applied were perceived as incompatible with extensive visiting hours. The observation *notes* are not fully transcribed and the analysis is not finished. A full report is expected in the first half of 2005 and will provide part of the *base line* for subsequent evaluations.

The researcher, Sven-Erik Olsson, participated in the first day of a conference in Ystad designed to "Start" Nearby Care development (Närsjukvårdsutveckling) in the Hässleholm Hospital Organization (cf Hälso- och sjukvårdsledningen 2004). The requested feedback from the observations by the researcher was presented by one of the participants in the Heart failure Chain. This was scheduled to the second day.

Current Plans and proposed outputs

The plan is to compile and analyze the CUU-observations and make a full report in the first half of 2005. The researcher also plans to attend/participate in the already scheduled review sessions (Heartfailure Chain). A report on the initial and second phase will be compiled and is expected in the third quarter of 2005. Attempts to follow the future of the endeavours of the Heartfailure Chain will be made. With regards to the HOP Steering Group things appear more uncertain due to the recent closure and other considerations. No report is planned but if the group decides that it wishes the researcher to participate in sessions later on, then this may be reevaluated.

The part on Patients Voice is expected to be further developed during the first half of 2005. This may affect the ability to continue to follow the HOP Steering Group, since the researcher is only employed half-time in research.

The plans concerning Patients Voice include:

- (1) Interviews with members of the two voluntary organisations Early retirees society of Hässleholm (Förtidspensionerades förening i Hässleholm, FTP) and Heart and Lung Sick's Society in Scania (Hjärt- och Lungsjukas förening, Skåneavdelningen
- (2) Interviews/conversations with strategic selection of citizens in Hässleholm, Osby and Perstorp.
- (3) Document studies when relevant. Already documents have been provided by the Heart and Lung Sick's Society.

A report is expected in the second half of 2005.

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3.2.2 The Närsjukvård pilot implementation project in the municipalities of Hässleholm, Osby, Perstorp

Närsjukvård organizational changes around wound care

Birgitta Höglund

3.2.2 Närsjukvård organizational changes around wound care

- Lead Reseracher/s: Birgitta Höglund
- Co-reserachers: Pia Petersson, Sven-Erik Olsson, Ingela Olsson

Originating agent

The “Närsjukvårds” -group in Hässleholm

Reference group/ participants

Eva Theander: leader of the nearby care project in Hässleholm – Osby – Perstorp, The “wound-group” in Hässleholm has three participants. Marie Lindell: chief at a primary care centre (vårdcentral), Vänhem, in Hässleholm, district nurse; Ann-Christine Danielsson, district nurse in the commune and Helena Roos, specialist nurse in wound care at the hospital in Hässleholm

Originating agent

The initiative to the project came from the Närsjukvård pilot project group in Hässleholm were given the task to develop the nearby care in north east of Skåne, within a frame given by Skånsk livskraft- vård och hälsa. The goal of Skånsk livskraft is to give the patients a higher quality care, as well as to develop cooperation between different actors and institutions within the health care organizations. The patient is supposed to get care from the right “level” of expertise in the organization; common problems and illnesses are supposed to be treated by the lowest “level”, closest to the patient – nearsick care.

Three different local municipalities were chosen for the pilot project: Hässleholm, Osby and Perstorp. The närsjukvård care group was interested in an evaluation of the changes in the care, as well as of the process. The changes in the way of working in care were supposed to have impact on different levels and actors: patients, relatives, co-members as well as the organizational level. Three different and common problem areas were chosen: heart, stroke and wound.

Introduction and rationale

The wound care area was chosen for two reasons: the wound group had already been working with care development for some years. The second reason is that patients with wounds are a big group; wound symptoms are a common problem in the care outside the hospitals.

In the area of wounds the development and changes have been in progress since 2001. A specialist nurse in wounds was given the task of identifying existing cooperation around the wound-treatment in the region, and to develop a plan of action. The wound group started as cooperation between actors from different institutions within the health-care organization in the north east of Skåne: primary care, commune, and hospital - one person from each institution. Two of the participants had a history of working in other projects, whose topics were related to the wound project. All of them are educated in the area of wounds. This group also belongs to another wound group, the wound network located at the hospital in Kristianstad.

The goal of the wound group is to *develop a common way of working with the treatment and care of wounds*, so everybody in the health care organization does it in the same way wherever they are located. The aim is that the wound care shall be of good quality and with the patient at the centre.

In the development of the Närsjukvård in north east Skåne, the initial vision was formulated at the top level in the organization (Skånsk livskraft). Some main concepts of value (värdeord) have been identified. Their role is to function as guidelines for all care in the region. In their work to improve the wound care the participants have translated the concept of values given by Skånsk Livskraft into practice. New methods, for example routines and bandage, of the care have been implemented. One important thing is the bluebook, with detailed information about wound care and treatment. Every institution, ward etc, in north east Skåne has got their own bluebook. Another element is the wound journal, which shall follow the patient; if he or she needs care in another institution the wound care shall be the same. The third element is that the name of the personnel, responsible for the patient and the wound, is written on the journal as well as told to the patient. At every institution, ward etc, one person has the responsibility for the area of wounds. The fourth change is that the specialist nurse visits patients in their homes and if the patient needs to see a physician, this shall be done within a four hour limit.

These changes in the ways of working with wound care have been disseminated to staff and personnel responsible for the wound care in the region at seminars.

Key research aims and objectives

The research project will provide insights into organizational change and the development of the nearby care. An evaluation of the impact of the changes, in the way of working with wound care, on the staff and personnel will take place. The way the staff and personnel at different levels in the organization (personnel responsible for the wound care at different institutions as well as "ordinary" personnel) experience the changes of the care is the main aim of this research project. To understand this we also need a description of the ways of taking care of the patient and his or her problems.

Current Research Questions

- How are the visions and concepts of value about nearby care, formulated by Skånsk livskraft, understood and translated into practice by the staff and personnel at different levels within the health care organization?
- Where do the ideas, knowledge and decisions to the changes of the wound care come from (Lipsky 1990)?
- How are the changes communicated between different levels, groups and individuals within the organization?
- How are the changes understood and experienced by staff and personnel?
- How do the staff and personnel perceive the wound care, the ways of working, and the needs of the patients?
- How does the cooperation work between different institutions, levels and professionals, as well as ordinary personnel and patients?

Stakeholders

The health care organization in north east of Skåne consist of different “levels”/stakeholders, in this context important for the development of the wound care, the Region Skåne and Skånsk livskraft, the nearby care group, the wound group, personnel responsible for the wound care, “ordinary” personnel and patients.

Theoretical perspectives

The official vision and concepts of value, formulated by Skånsk livskraft, are abstract and general in their nature. They need to be translated into models that can effectively be implemented in practice while remaining true to the original vision. (Gubrium & Buckholdt 1982; Miller 1991; Närvänen 1994). Often different translations and interpretations exist in parallel or at different levels at the same time. At a hospital Gubrium and Buckholdt (*ibid* s 11) noticed: “Staff members are able to describe patient problems and the hospital’s therapeutic efforts in ways that are not completely compatible with each other, some of which would be officially unrecognizable.” Depending on where you are, who you are, what role you have, your tasks at work etc; there are different systems of meaning to use to interpret your experiences. Anspach (1993) states that it is the tasks at work that put pressure on the individual to develop a certain perspective at work (situational perspective). To understand different perspectives you need to know how the individual is related to the context. (Gubrium 1988; 1991; Anspach 1993) Sometimes different local cultures coexist within the same organization; they grow from the recourses in the environment (*ibid*).

When people describe what they are doing they tell you something about their own pictures and interpretations of the reality, the way they understand it (Miller 1991). What we know about things come from how they’ve been described to us. Things, which at the surface look like objective information, are more than that. When describing something, at the same time, you give it meaning. Descriptions don’t only produce facts; they also consist of ideas, standpoints and opinions. The information filtrates through the perspective of the teller. Through choices as what to tell, how to tell etc. that makes descriptions constructions of the reality (Hammersley & Atkinson 1995).

The notion of change often leads to thoughts in terms of big organizational changes, but often the actual change isn’t that great. But irrespective of whether the change is a big or a minor one, it can affect the definition of the reality that exists at, for example, a working place. Also the staff can experience small changes in the routines as they’re called into question. The staff can react in different ways and with resistance. (Närvänen 1994).

Earlier the goal of the wound group was described as to develop a common way of working with the treatment and care of wounds, so everybody in the health care organization do it in the same way wherever they are located. For this goal Barnard (1968) use the concept *a zone of indifference*. But Goffman (1988) is of another opinion, saying it isn’t a realistic goal; to reach consensus in every routine and detail in the working methods is more a vision. Instead he uses the concept *preliminary working-unit* or *casual consensus*.

Rules, routines and ways of working, can be understood as a certain definitions of the reality. With the help of routines etc, you create order in your environment, at the same time you reproduce the social order - the routines function as some sort of social control. (Berger & Luckmann 1987).

Research process

The first part in the research is to get acquainted with the area. A number of qualitative interviews with key informants (the wound group) and some observations have taken place

January 2005: Data analysis and feedback to the wound group.

January-mars 2005: Interviews with staff responsible for wound care at different institutions, analysis and feedback.

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3.2.3 The Närsjukvård pilot implementation project in the municipalities of Hässleholm, Osby, Perstorp

Wound Care process, how patients experience leg ulcer care

Pia Petersson

3.2.3 Wound Care process – how patients experience leg ulcer care

- Lead researcher: Pia Petersson
- Co-researchers: Birgitta Höglund, Sven-Erik Olsson, Ingela Olsson, staff at the care centre Vänhem in Hässleholm, municipality district nurse, hospital wound nurse

Originating agent

The CUU-ward in Hässleholm, project leader Eva Theander

Introduction and rationale

One of the underpinning notions of Närsjukvård is that the care should be planned from the point of view of the needs of the habitants. Care should be provided close to those who need to visit the health care often and over a long time period, provide a welcoming atmosphere, be easy to reach, offer a participatory service and have a holistic view on the needs and desires of the individual. Region Skåne expects that these aims could be reached by evident care programs and care processes. (Regionfullmäktige 2004). This particular study will contribute to an understanding as to whether this has been achieved.

In Skånsk Livskraft there are a number of projects aimed at improving the care and its effectiveness. An example is the development of a care program for leg ulcer treatment.

Many persons with leg ulcers get their treatment within the primary health care system, in their home or in clinics. The cost to the health service of treating leg ulcers is considerable. Costs for leg ulcer treatment include care in primary health care or in hospitals, drugs and bandages. Costs also includes issues such as decreased productivity due to poor health but this cost is more difficult to estimate. One measure of the costs for ulcer care is the time taken for wound management. In one study 287 patients with chronic leg ulcers demanded 12 full-times nurses. (Öien R F, Håkansson A, Ovred I Hansen B U 2000) While costs and efficiency are important so is the quality of the care and a balance needs to be struck to combine the two.

In Hässleholm a specific group works with the leg ulcer treatment. They have developed a care program, which includes which bandage is recommended and also a specific record for the patient with leg ulcer.

Key research aims and objectives

An investigation how the patients experience the leg ulcer care will be part of the development of the wound care program. In keeping with the approach of the research platform a baseline study will be undertaken focussing on this main question. Based on the results from this investigation, further research questions may be defined regarding how the patients' experiences can be used to develop care staff's praxis.

Theoretical perspectives

A leg ulcer impacts on the day to day life of the person who has it. Patients mentioned pain as the first and most dominant experience related to having a leg ulcer. (Pearson, Heinen & Carien et al 2004., Ebbeskog & Ekman 2001., Lindholm, Bjellerup, Christensen & Zederfeldt 1992). Tiredness is a major factor in daily life but also disturbed sleep and impaired mobility (Lindholm, Bjellerup, Christensen & Zederfeldt 1992) (Pearson A, Heinen M M, Carien J M et al 2004).

In many studies patients have reported feelings of regret, depression, loss of will power, loss of control and feelings of helplessness and hopelessness (Pearson A, Heinen M M, Carien J M et al 2004).

A lot of these different factors impact on the social life of the patient with leg ulcers. The patients experience increased social isolation because they do not want to display the exuding ulcer, the bandage and the dressing. Having a wound itself generates negative experiences. Wet shoes, stockings, sheets and bed covers can cause embarrassment. Sometimes the wound also smells unpleasant. (Pearson A, Heinen M M, Carien J M et al 2004).

Most of the patients have a negative view of the healing process (Pearson A, Heinen M M, Carien J M et al 2004) and some have identified themselves as a "leg ulcer person" (Ebbeskog B, Ekman S-L 2001) but in some cases coping strategies were mentioned (Pearson A, Heinen M M, Carien J M et al 2004, Ebbeskog B, Ekman S-L 2001). Some patients are able to accept leakage and discharge as part of having a leg ulcer. They also try to have a positive attitude to carry on and to make life changes to find new satisfaction (Pearson A, Heinen M M, Carien J M et al 2004). Some persons thought it was important for their wellbeing and the healing to maintain their daily habits (Ebbeskog B, Ekman S-L 2001).

Patients describe dissatisfaction with the professionals because they don't always explain what treatment to follow. Lack of listening, providing inconsistent messages or advises have also been mentioned. In other ways patients were grateful, often due to a positive personality of nurses and other professionals (Pearson A, Heinen M M, Carien J M et al 2004).

Research process

The professionals have made a great number of improvements in how they care for the patients' leg ulcers but little is known of the impact on the actual patient experience. After a discussion with the group in Hässleholm it was decided to make qualitative interviews with patient who have leg ulcer.

When the interviews are completed and analyzed a workshop will feedback the findings to the professionals. In light of the results the implications for practice will be explored in collaboration with the professionals. The patients who were interviewed will also be given the opportunity to comment on the findings.

Outputs of the research process to date

The interviews will be analyzed in January 2005 and will provide information concerning whether the developed care program have made any differences for the patients.

Current Plans and proposed outputs

This study will form the basis of a publication for an academic journal. The research is planned to be finished in June 2005.

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3.2.4 The Närsjukvård pilot implementation project in the municipalities of Hässleholm, Osby, Perstorp

Care Processes in Hässleholm, Osby and Perstorp, patients with chronic illnesses

Pia Petersson

3.2.4 Care Processes in Hässleholm, Osby and Perstorp, patients with chronic illnesses

- Lead Researcher: Pia Petersson
- Co-researchers: Birgitta Höglund and Kerstin Blomquist

Originating agent

The originating agent was CUU-ward in Hässleholm. Project leader Eva Theander in Hässleholm

Reference group

To be determined and expected to include patients

Introduction and rationale

This study has a similar rationale to the previous two as it is focussed on how Närsjukvård has actually been translated in to practice in terms of the actual care processes the patients experience within the HOP initiative. The purpose of the initiative is to introduce changes in the care processes for heart failure, stroke and wound patients. In this particular study the focus will be patients who visit the primary care and are included in these different groups but particularly those with multiple chronic illnesses. This research is in its very early stages.

Key research aims and objectives

To investigate how patients with chronic illnesses understand their illness and to what extent they participate in their own care. It is intended also to examine the impact knowledge of this understanding has on the professional's behaviour.

Current Research Questions

1. How do patients understand their illness?
2. What is the relationship between a patients understanding and how they behave.
3. How participatory is the decision-making and care process both from the patient's and professional's perspective
4. To what extent does and understanding of the patients' view bring about changes in professional practice?

Theoretical perspectives

People with chronic illnesses consume a lot of health care, especially primary care but also specialist care in general hospitals (Paulson et al. 2002 Previous research shows that at the same time patients with chronic illnesses experience a daily struggle against tiredness (Melanson & Downe-Wamboldt, 2003) social isolation (Strömbäck & Malkan, 2003, Ebbeskog & Ekman, 2001) and in managing their illness they sometimes feel misunderstood by professionals and are

disappointed with a professionals behaviour in their care (Paulson & Danielsson, 2002. Rogers et al., 2000). Patients consider time, continuity and participation as an important dimension their care. (Bergman & Larsson, 2002).

In the research literature there is a debate as to how health care can be improved by organizing the health care differently particularly concerning which care level will take the lead in the care of the patient: primary care, specialist care, nurses, physicians or care team (Anderson Rothman & Wagner, 2003, Halcomb et al., 2004, Kayton et al., 2001, Anell, 2004). There are also attempts to understand different aspects of care, for example why patients are satisfied or dissatisfied with their care (Rogers et al., 2000, Wilde et al., 1993) and how patients experience their illness and life (Melanson & Downe-Wamboldt, 2003, Strömbäck & Malkan, 2003, Ebbeskog & Ekman, 2001). Various interventions such as traditional information, problem-solving and goal-setting as well as cognitive-behavioural therapy for patients to better manage their chronic illness (Newman et al., 2004) have been used.

The Swedish law on health care emphasizes that treatment shall "as long as possible formulate and realize the care in cooperation with the patient" (HSL 1982:763 own version). Patient centred care is one way of doing this. However, previous research has shown that this patient-centred care has different meanings for different professionals and patients. The meanings and understandings cover a range of activities from patient involvement in individual care to public involvement in health care. (Gillespie et al., 2004). One suggestion for getting patients to participate in their care is for professionals to invite them as equal partners and assume that this is sufficient to reach empowerment (Paterson 2001). However, Paterson shows that although professionals think in an empowering way it is not so easy to act so as to empower. Michie et al. (2003) have shown how patient centred care is associated with beneficial physical and psychological outcomes. They found that patient satisfaction can be high even when the medical treatment generated poor clinical outcomes and low even if medical treatment is considered effective and good.

One aspect of care in which this is relevant is self-management. In a literature review Newman et al (2004) that self-management is difficult. When looking at all self management interventions in one analysis, they were still unable to identify which of the different types of intervention for increasing self management were effective and for which outcomes. However as has been shown what is a good outcome for the patient may not be the same from a medical perspective. If the clinical outcome in terms of self-management, such as taking medications or having good blood glucose level is not achieved, health care professionals commonly interpret this as the patients being non-compliant. Indeed non-compliance of patients with prescribed treatments is considered as a barrier to effective health care (Playle & Keeley 1998). Since for the health care professional a compliant patient is a way to achieve a satisfactory outcome, much research has been undertaken to find out how to get a compliant patient.

Evangelista (1999) has done a concept analysis on compliance. She quotes Haynes, who has defined compliance in health care. "Compliance is the extent to which a person's behaviour (in term of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice. Or in a simpler form, compliance means "patients doing what the health professional want them to do". If the purpose of the treatment is only seen in that way it cuts out a whole range of important dimensions. The patients own life is missing including the context they live in, because there is a broad set of constraints which influence treatment, including work, housing, finance, family and emotional factors (Bissell, May & Noyce 2004).

It is obviously difficult to get answers as to the best way achieve a satisfied patient with sufficient medical outcomes. Is it depending on patient's difficulty in understanding and managing their illness? Or is it due to a lack of knowledge on the patient's part? Horowitz C R,

Rein S B and Leventhal H (2004) found that patients with heart failure were not given strategies to deal with any complications that might arise and therefore accessed hospital services unnecessarily when unexplained changes took place. On the other hand Tang S and Anderson J (1999) have shown some patients don't want to take any responsibility for their illness and place see that responsibility entirely that of the professional.

This research contributes to the knowledge as to the patients understanding of their illness and how that understanding can contribute to more effective care.

Planned Research process

The research has not been started yet but is likely to follow the following three research cycles and will proceed from year 2005 to 2008.

Circle one: Patients will be invited into focus groups and interviewed about their understanding. The material will be presented to patients and professionals in different workshops and the action that follows will be decided together with the patient and professionals.

Circle two: An observational and documentary study will be made of how patients participate in their care. The results will be presented to patients and professionals in workshops together. Some action will be planned.

Circle three: An exploration of how the professionals act when they meet patients in a treatment situation by observations and interviews with the professionals. The feedback will be to professionals and action taken will be planned.

All the circles will be evaluated to see how the process has gone and if knowledge has increased and what changes, if any have taken place.

Current Plans and proposed outputs

How the research is planned describes in a work plan for this specific research. (Appendix 1)

The research will be presented in four articles. The three circles in three different presentations and the fourth article will be about the evaluation.

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3.3 Psychiatric care organisation in Hässleholm

3.3.1 Public Sector Collaboration within Psychiatry and the impact on the patients of the Psychiatry and the clients of the Social services within NÖ Skåne

Lisbeth Lindell

Ann-Marie Ek

3.3.1 Public Sector Collaboration within Psychiatry and the impact on the patients of the Psychiatry and the clients of the Social services within NÖ Skåne

- Lead researcher: Lisbeth Lindell
- Co-researchers: Ann-Marie Ek, PhD Student, Department of Business Administration, Lund University

Originating agent
Municipalities and psychiatry

Reference group/participants

- 1) Officers and professionals from the municipalities and representatives from child-, adolescence- and adult psychiatry
- 2) Patients/clients, parents/relatives

Introduction and rationale

The Psychiatry Reform 1995 made the shared responsibility between the municipality and the psychiatric care more clear regarding mentally ill people. Both before and after the implementation of this reform, the lack of collaboration between the local authority and the county council has been the focus of recurring reports, and attempts have been made to unite efforts on a national level as well as on the local level. With this as a background, a project has been drawn up in collaboration with the main agencies, the municipality and psychiatry.

The project consists of two separate parts. One part aims to examine the lack of collaboration, which is made evident in the problems of prioritizing and allocating between the local authority and the county council. It was originally intended that the second part of the project would examine the effects of the collaboration – or the lack of it – between the main participants, and also how these affect the patients/the parents/the relatives. This part of the examination was driven by the idea that it is important to pay attention to what the people with serious mental and social problems or diseases have to say about their own situation, in order to guarantee the influence of the user. This element will now through discussion be incorporated into an evaluation of an innovative collaborative psychiatric project focussed on intermediate care in Bromölla. This project is actively involving the user in its development.

Key research aims and objectives

The aim of the first part of the study is to examine collaboration by making an inventory of the processes, by making the boundaries more distinct regarding responsibility, and by making the forms of collaboration between the municipality and the child- and adult psychiatry more obvious. Participating people in this part of the project are officers from municipal social services and the child-, adolescence- and adult psychiatry in the north eastern part of Skåne. In this part of the study a researcher is participating in a series of meetings, where representatives from the psychiatry as well as from the social services are meeting to discuss and implement collaboration (Ann-Marie Ek).

The aim of the second part of the study is to examine collaboration from the perspective of the out-patient/the client/the parent/the relative, and to examine the experiences of being an out-

patient/a client/a parent/a relative. Questions can be answered through observation, focus groups and individual interviews of patients/clients/parents/relatives. (Lisbeth Lindell).

Current Research Questions

The research question in the first partial project is:

- How do linguistic differences operate as boundaries in collaboration.

The research questions, which are still being negotiated in the second part of the project, are:

- How are patients/clients/parents/relatives constructing the boundaries between the psychiatry and the social services?
- Do problems regarding collaboration exist? If so, how is this manifested?

Other questions, which can be raised in order to illustrate the main question, are:

- What experiences do the patients/clients/parents/relatives have from the treatment and the rehabilitation?
- Are there any health promoting elements in the treatment and the rehabilitation?
- What are less good/bad?
- How would the patients/clients/parents/relatives have wanted the treatment/rehabilitation to be designed?

The overall objective of the project is to develop an understanding of the prerequisites of Närsjukvård in order to meet the needs of outpatient health- and social care and enable collaboration between the staff and mentally ill people. This in turn is expected to enable the professionals to offer an improved care/treatment/rehabilitation, and also to utilize the available resources more effectively.

Theoretical perspectives

The theoretical perspectives are currently to illustrate and discuss how boundaries are constructed and how collaboration is put into practice from the professional level and from the patient's/client's level. Collaboration (in Swedish: *samverkan*) can be seen as a political/managerial vision that aims at making members from different organizations work closer together. Currently in Swedish public sector collaboration is advocated in a mantra like manner. At the same time many studies show that it is difficult to make collaboration work. This research has examined the collaboration processes in practice. Collaboration can for example mean that representatives from different organizations meet to discuss how to act together, but what happens in the meeting situation and what role does language play and how does it change? With these kinds of questions

in mind a field study was initiated which focused upon collaboration between social workers and psychiatric care.

Research process

Two collaboration groups were studied. One discussed collaboration around children and the other talked about collaboration around adults. All together the researcher participated in thirteen meetings that took place in a time period of eight months. Most of the meetings have been tape recorded and transcribed. In addition internal documents were studied for example agendas, meeting protocols, priority lists and so forth. During the meetings the researcher was able to pose questions and talk to participants of the meeting during coffee breaks. After most meetings the researcher wrote down reflections and sent these to the participants. In the reflections no answers were provided answers merely talked about different ways to approach a problem that had been expressed during the meetings. This provided input into the discussion and provide in formation to facilitate the discussions and also stimulate the participants to reflect upon the discussions. The fieldwork is now completed and the material is currently being analyzed.

At the moment the planning on the research process for the second part of the research is still at the dialogue stage. The process will as far as possible follow the participatory action research process, and using observation, focus groups and individual interviews.

Outputs

The first piece of research will form part of a Lund University Thesis. It is possible to say at this stage what will be part of the second piece of work.

3.4 The R&D (FoU) Networks

3.4.1 An Evaluation of a number of clinical R&D Networks and their impact on a reorganization of the Health care system in southern Sweden with particular reference to Development, Learning and Change

Yvonne Johansson

3.4.1 An Evaluation of a number of clinical R&D Networks and their impact on a reorganization of the Health care system in southern Sweden with particular reference to Development, Learning and Change

- Lead Researcher: Yvonne Johansson
- Co-researchers: Leif Karlsson, Jane Springett

Originating agent

Viveca Dettmark, convener of the R&D Networks and the steering group

Reference group/participants

The coordinators of the R&D Networks

Introduction and Rationale

The development of Närsjukvård supported by some R&D networks

The development of the *Närsjukvård* allows change agents to come up with different projects supporting this initiative and in the northeast part of *Skåne* a number of R&D networks have been formed for that reason. At present they are nine in number and they are working with the following subjects (fig 1):

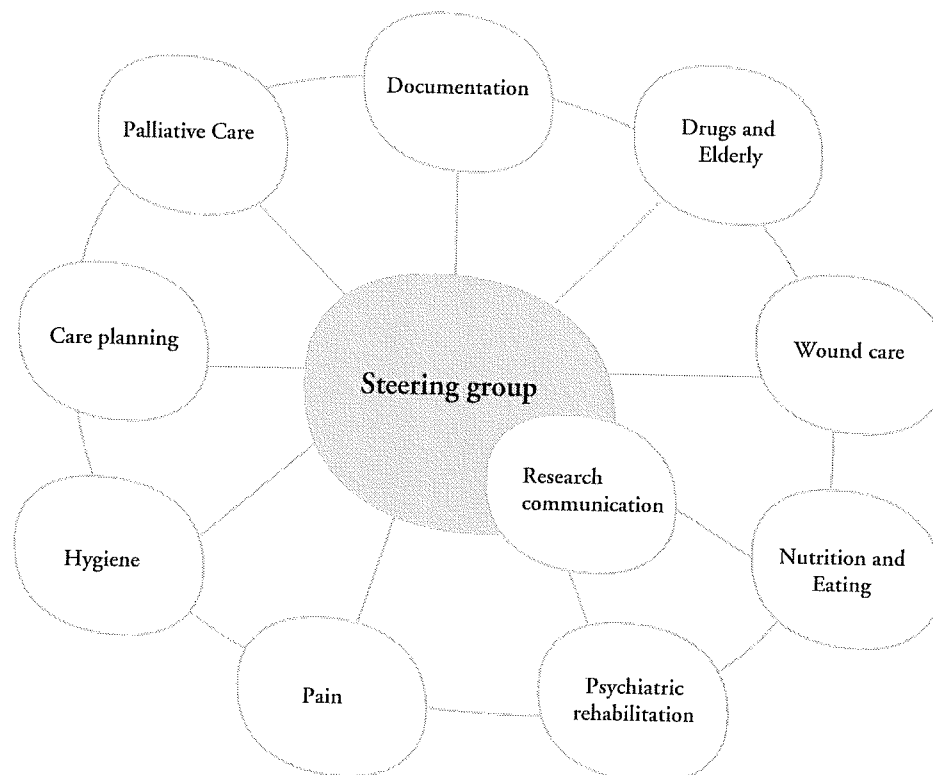


Figure 1. A model of the R&D networks and their specific subjects, created by members in the steering group.

The networks constitute a platform for bringing together the hospital care, the primary care and care provided by the municipalities and each network consists of a coordinator and a group with a varying number of members with professions like nurses, occupational therapists, dieticians, pharmacists and physicians. Some of these members have created their own networks including people employed by the different health care providers mentioned. Most of these members have a nursing background. A number of representatives from the three care providers constitute a steering group for the R&D networks.

Besides expectations about taking action concerning development connected with their specific areas, the networks are expected to promote professional approaches to care and strengthen the collaboration between these health care sectors. Through developing their abilities to co-operate they intend to increase the conditions of exchange of knowledge and development of competence (Måldokument FoU Nätverk, 2002).

The platform consists of two components of which one is research and development and the other is spreading out results. The networks will follow the development related to care and work for implementation of methods that are on a line with research and well-trying experiences. Different experts from the health care sectors and a neighbouring University will be used, likewise the commitment and views from different client groups. Moreover, an aim is to create consensus concerning common strategies emanating from the patients and caretakers needs (Ibid.).

The R&D networks are supposed to represent a new way to think and act, and from that point of view their function can be regarded as an intervention in the existing health care system in the region.

Health care systems in change

In Western Europe there has been a considerable increase in the number of chronically ill patients with multiple demands and this has raised a number of issues about how health care is delivered. In the Netherlands, for example, there have been two dominant concerns regarding this group: how to contain the cost of professional care; and how to make the system and institutions more responsive to the needs of this patient category (Hardy, Mur-Veemanu, Steenbergen & Wistow, 1999). Just as in Sweden these kinds of discussions have led to a conversion from supply towards demand orientation, i.e. that the receiver rather than the supplier are placed at the centre (Meijboom, de Hann & Verheyen, 2004). Thus health care is entering a new era, which Pavia (2001) has called a consumer-driven era of knowledge. As a result of this new ways to cooperate and organise the existing health care systems are required. One response is the development of notions of network management (Meijboom, de Hann & Verheyen, 2004).

Meijboom et al. (2004) define a health network as a formalized cooperation between independent health care providers. The word networking is problematic however as different people use it in different ways. It can be regarded as a social process of linking and connecting individuals together, but also as assembling coalitions or groups in order to achieve tasks (Hastings, 1993). It is worth noting that the R&D Networks in this study seems to be in accordance with the last definition.

The impact of clinical network management in the health care sector is not explored to a great extent. Transitions to network management can be considered as something desirable or even necessary though it challenges old ways of thinking, but it has also been questioned if it is at all possible to implement in a health care context. The complexity associated with health care become visible in Hardys' et al. (1999) description of different obstacles concerning integrated care development and delivery within the health care systems in England and the Netherlands. Some of the hindrance identified derived from the social, economic, political, local and legal context. Besides, the predominant complexity of the system with a lot of stakeholders having different roles, tasks, interests and power positions were considerable.

Perrucci and Potter (1989) focus on power by raising the question as to what extent the properties of networks influence the persons or organizations that comprise the network. Another of their questions that require further studies is how networks are able to mobilize resources to influence actors and actions that are external to the network. When it comes to realization of network aims and interests, the support is of great value (Hall, 1987). Network members need to be compelled either by voluntary support or an external authority. An aspect of importance is the managers' willingness and ability to use communicative, negotiating and other political strategies (Ibid.).

All vital organizations are dependent on a free flow of information and a continuous supply and development of knowledge (Kline & Saunders, 1993). Mayo and Lank (1994) assert that it is possible to establish a foundation for change and development and increase the knowledge through a constant internal dialogue. Swieringa and Wierdsma (1992) argue that a group can achieve what none of the individuals could easily accomplish. Though R&D networks in this study are involved in a health care system in change they also are concerned with learning.

Learning

The way working teams collaborate has implications for the learning process. The maintenance of the learning process is strengthened by an affiliation to a group where everybody is interested in the same tasks (Moxnes, 1984). Furthermore, group decisions offer more effective changing strategies compared to influence through information and persuasion (Ibid.).

From a learning model, derived from Kolb, learning can be regarded as a cyclic process: doing – reflecting – thinking – deciding – (re) doing. Learning is therefore a never-ending and constantly repeated process. In this learning model the acquisition of knowledge and insight is integrated with the development of skills and attitudes. The central idea of the Kolb model is that it considers that everyday activities can be a component of learning processes, and that it states how these often unconscious activity processes, in conjunction with thinking and deciding, can be raised to the level of conscious learning (Swieringa & Wierdsma, 1992).

Learning processes related to changes in places of work are affected by the extent of participation, the opportunity to try out one's own solutions and to discuss different experiences (Kronvall, Olsson & Sköldborg, 1991). Furthermore, evaluation can be considered as an ongoing learning process with possibility to contribute to quality assurance through quality assessment and evaluation are complementary and linked (Springett, 2003).

Development: knowledge production and practice change

A question of interest is how stakeholders in health care systems, organised in networks, succeed in the progress of network activities and learning processes when they are confronted with existing traditional structures. Traditionally the management of change in health systems has largely been in the form of a command and control model of implementation. However, new concepts are increasingly being experimented with. The rationale for a different approach is that change does not take place linearly within complex adaptive systems such as health and social care, rather the process of change is a product of the relationship between the actors in the process, the information available within the system and the learning and reflexivity taking place.

The complexity of changing practice successfully has been widely acknowledged in empirical studies of health care practice (Redfern & Christian, 2003). Pettigrew et al. (1992) have created a model on receptive context for change including eight factors: 1. Quality and coherence of policy. 2. Availability of key people leading change. 3. Environmental pressure. 4. Supportive organizational culture. 5. Managerial – clinical relations. 6. Cooperative inter-organization networks. 7. Simplicity and clarity of goals and priorities. 8. Change agenda and its locale. These identified factors should be seen as providing a linked set of conditions, which together provide

high energy around change. Pettigrew et al. (1992) describe the factors as a series of loops rather than a casual path between independent variables.

Organisations, in particular professional non-profit institutions, currently rely heavily on knowledge (Nooteboom, 1999). People not only possess information itself, they are also able to integrate and frame the information at hand within the context of their experience, expertise and judgement and even create new knowledge (Meijboom, de Hann & Verheyen, 2004). Individuals caught up in change in a complex way, reflexively construct their own identity that may or may not fit in with the overarching vision and new reflexive communities will emerge to make sense of and reshape the centralised forces. Creating reflexivity within the system can be regarded as a key part of knowledge development (MacKian, Elliott, Busby & Popay, 2003).

The management of knowledge is complex because of the distinction between tacit and documented knowledge (Meijboom, de Hann & Verheyen, 2004). In the health sector, professionals deal with knowledge when performing their tasks and for the various types of professionals differences exist in domains of knowledge as well as in degree of tacit and documented knowledge (Ibid.).

Key research aims and objectives

The purpose is to find out how development, learning and change take place within the R&D Networks and ascertain how the aims of the networks are being translated into practice. An intention is to examine which elements, conditions and ways of working have an influence on changes taking place, in order to develop a model for good practice.

Current Research Questions

- Which development and changes are taking place within the R&D networks?
- Which elements, conditions and ways of working have an influence on the changes taking place?
- How and in what way does learning take place?
- To what extent does the work of the R&D networks have an impact on the health care system in the northeast of *Skåne*?

Theoretical perspectives and approach

Critical realism will constitute the theoretical base in this study since it provides a useful framework for understanding the complexity in changes taking place by its derivation from contextually specific stance (Winter & Munn-Giddings, 2001). A starting-point is that there are interactions between the initial conditions, contextual constraints and what we actually do, which present possibilities to bring about changes in particular contexts (Ibid.). From a critical realism perspective our understanding develops through a dialectic process between creative conjecture and practical action (Ibid.). Critical realism also has the potential to embrace qualities that become visible within an emancipatory approach, like showing consideration for the perspective of participants (Robson, 2002). This research position leads to the approach P.A.R. that is located in practice, where dialogue, democracy and participation of the stakeholders are considered to be

of great importance (Greenwood & Levin, 1998). Practitioner-centred research is advocated on the basis that it produces a different type of knowledge more useful to practice (Meyer, 2001).

In this study the coordinators of the R&D Networks and the members within these networks will be involved in workshops, reflection sessions, the decision-making concerning interventions and action to be taken. The role of the researcher will be to facilitate the process, and the understanding that is obtained will be used to suggest ways for change (Robson, 2002).

The initial process of focusing, framing and designing an action research study is often associated with a cyclical process including the aspects observation, reflection and action (Stringer & Genat, 2004). The number of steps in these cycles and how they are named may vary, but the principle is the same. Following research cycle, presented by Robson (2002), will be used in this study:

- Planning a change
- Acting and then observing what happens following the change
- Reflecting on these processes and consequences
- Planning further actions
- Repeating the cycle

The focus will be on two groups, the coordinator group who are the network managers and a particular network to be selected. Initially a data collection in each group will be undertaken in order to get an overall view of the networks and map out peoples assumptions and ways of working. To get possibilities to identify development, learning and change taking place a review in each group will be carried out. The feedback of data to the stakeholders involved will be continuous and also be an interactive process between the two groups. It is intended that the research will end in a model of good practice. In the figure below (fig.2) the four research cycles appeared and their relations in time are illustrated:

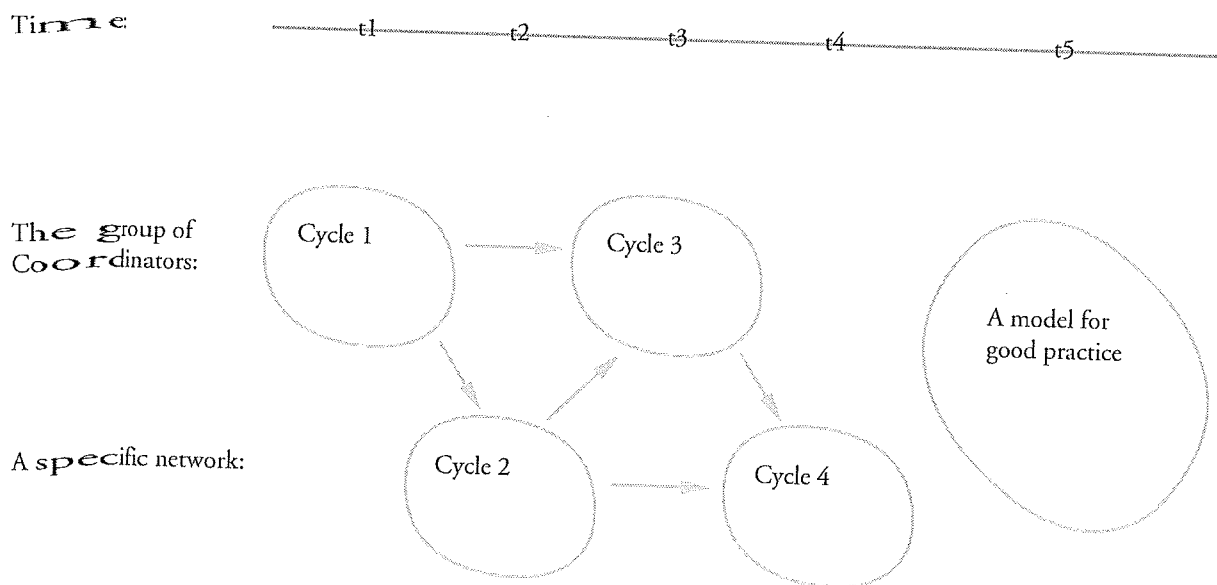


Figure 2. An illustration of the research cycles and their relations in time. The arrows show the overlapping feedback that will be undertaken in addition to the feedback that will take place within the cycles.

The approach chosen embraces an evaluation dimension that can be described as a research driven evaluation where an action research approach is used. Sometimes a discussion whether evaluation is a separable activity from research or not is raised. Robson (2000) writes that this distinction turns on the breadth or narrowness of view of both evaluation and research that are adopted. He asserts that an investigation of a program done with carefulness can give worthwhile information equivalent to research as long as we do not tie ourselves to a restrictive definition of research, such as one which only considers randomized control trials focusing on program goals to be admissible.

Methods

The research will take a multi-method approach by the use of observations, interviews and documentary analyses, which according to Robson (2000) are the main methods used in small-scale process evaluations. Given that a participatory approach is being adopted the specific methods will be chosen and developed in the course of the research project. The results will be mirrored back to the stakeholders and reflected on regularly with the purpose to generate learning and action. As Fals-Borda (1991) writes it is a duty to feedback the knowledge to the society, though they continue to be the owner of it. Reflections on the decisions to change coming from the group, the impact of the context and the action research process it self will be continuously monitored as well as me as a researcher and facilitator will be reflecting my own part of research. As a social scientist I will bring a social perspective to the research process.

Research process and outputs

As a first step observations have been undertaken during the regular coordinator meetings that took place during the year. The purpose was to get a baseline of what the R&D Networks strive for and actually do. After an agreement with the coordinators, interviews concerning their own

assumptions of the work they accomplish, were done in May and June 2004. When analyzing the interviews it appeared that the coordinators regarded it as very important to strengthen the members in their nearest network, i.e. the individuals they have meetings with on a regular basis. They considered it as important to obtain knowledge, for example from research and lectures, and spread it through their networks so that it reach and become benefits for the patients and caretakers. However, they found it difficult to figure out how this could be handled most advantageously since there are a large number of individuals concerned with care within the area. Some of them articulated that they just have to rely on that the representatives within their networks actually spread the knowledge forward.

The interpretation of the interviews were presented for the coordinators the 19th of September and a model created as an illustration of this interpretation was discussed, first in small groups and after that in plenary meeting. The discussions resulted in an expanded model where knowledge, instead of being regarded as something that can be spread as a cascade from the top downwards, was considered as something that can be spread in various directions. An agreement to further challenge the model was made.

The process continued on the 14th of October and an initial question discussed was if learning comprise more than dissemination of information, even if it has different directions. This dialogue concluded that learning could arise from many aspects such as experiences, motivation, dialogue and reflections. The session concluded in a formulation of a common research question: – How can the conditions for learning connected with the work accomplished within the networks be improved?

The coordinators required a lecture on the subject of learning to form a basis of the next step where a decision about action to be taken will be made. A lecturer (and one of the supervisors for this research) from Kristianstad University will deliver a lecture the 20th of January 2005.

Thus, in view of the interviews a shift from the coordinators initial perspective has been observed. Their view of knowledge has been extended to include the assistance nurse's perspective in a larger extent. This means that development is being brought into a closer association with the patients and their immediate caretakers.

Referring to the research cycles, the coordinators have reached a phase in the first cycle where they are going to plan further actions. This cycle will be completed during the spring in 2005 and be followed up after two years.

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3.5 Fenix

3.5.1 Fenix – Psychosocial support and rehabilitation of cancer patients and their relatives

Lena Persson

Lena Wierup

3.5.1 Fenix – Psychosocial support and rehabilitation of cancer patients and their relatives

- Lead Researchers: Lena Persson, Lena Wierup

Originating agent

Staff, team members at FENIX

Participants

Rut Flensmark social worker, Eva Myrberg preast, Bo Olsson physician, Råger Wählin physiotherapist, Andrea Magnusson nurse, Ingrid Borg-Persson nurse, Karna Arvidsson occupational therapist, Annette Andersson division leader, Lena Wierup university lecturer, Lena Persson senior lecturer.

Introduction and rationale

Fenix is a unit for psychosocial rehabilitation for cancer patients and their relatives after the active treatment are ended. Both the patients and their relatives can contact the unit for support by them selves or with a letter of referral from a doctor.

The unit is organized in primary care but there is a need for improved collaboration with institutional care and the staff at the hospital to improve continuity for the patients. This collaboration can be conducive to an increased accessibility and care adjusted to individual needs.

Every year, more than 40 000 persons are diagnosed with cancer, and the lifetime risk to develop cancer is above one third. About two thirds of persons diagnosed with cancer are older than 65 years (National Board of Health and Welfare, 1999). Cancer is not one disease, but rather a group of more than 200 diseases. More than 50% of cancer patients can be cured from their disease. Even if not cured, many persons live and function well for many years. Cancer can thus be regarded as a chronic disease for many persons.

Rehabilitation is potentially important for patients with cancer, whether cure is achieved or several recurrences occur, as they must learn to live with a cancer diagnosis. Rehabilitative interventions, including psychosocial support, are performed with intention to facilitate cancer patients in coming back to a normal life within the limits imposed by the disease and treatment.

A cancer disease has a deep impact on both the patient and their relatives and may in turn lead to distress for all parties involved. The feelings of loneliness fear and uncertainty about the future, as well as their experiences of lifestyle disruption, communication breakdown, lack of support, and sense of helplessness have been reported by spouses (Persson 1998). Adopting a more holistic approach including the whole family may be more efficient way of empowering the patient and their relatives.

Key research aims and objectives

The aim is to support the development of models and approaches that can get in contact with persons treated for cancer and their relatives who needs psychosocial support and to develop alternative forms of support for an individual or as group activities.

Current research question

- How can collaboration between in hospital care and primary care for patients treated for cancer and their family be improved?
- What are relatives' expectations and how are their needs for psychosocial support were met and how they experienced the professional care provided?

Theoretical perspective

When one member in the family falls ill there will be role changes and changes in their mutual relationship. Many relatives experience their new situation as a burden related to increased responsibility and extended amount of practical care activities. Independent of where the sick person is at the hospital or at home the family has an increased need of information, communication and support. Their new situation in daily living needs an adaptation to the disease and the treatment. To focus on the whole family as an integrative system may be more efficient while having positive effects for the patient's rehabilitation and the wellbeing for the whole family.

Research process:

We have in dialogue and reflection together with the staff decided to focus on the relatives and their situation. The first step in the team was to discuss their experiences and discuss how they wanted to develop their own way of working with and giving support to relatives

Next step was to increase the knowledge of the relative's experiences and needs of psychosocial support. The first data collection has started with tape-recorded individual interviews with relatives to cancer patients. After the analyses the result will be presented for the staff.

After that a new data collection is planned to start with focus-group interviews with staff caring for the patient at the hospital. The aim is then to investigate the staff attitudes to the relatives and their need for social support from a family perspective.

3.6 Bromölla Municipality Care

3.6.1 Municipality based health and social care

3.6.2 The Opportunities for Patient's self-care

3.6.1 Bromölla Municipality Care

Municipality based health and social care

Irena Dychawy-Rosner

3.6.1 Municipality based health and social care

- Lead Researcher: Irena Dychawy-Rosner
- Co-researchers: Lennart Erlandsson, assistant lecturer and research student of law, Eva Skogh DSK; Marie Bengtsson, SSK; Irene Wahlgren, förvaltningschef, James Collins, utvecklingssekreterare; Mia Persson Fröjd, avd chef; Marie Hallerström, biståndshandläggare; Åsa Blomberg, OT; Malin Sundin, sjukgymnast; Gunilla Haraldsson, DSK.

Reference group/participants

Staff from different professional disciplines e.g, district nurses, home care nurses, social workers, an occupational therapist, a physiotherapist and other staff involved in caring processes in the field, municipally management staff, (e.g., principal from the municipally administration, förvaltningschefen) staff manager of the social care board (personal chef), manager of the health care department (verksamhetschef etc).

Originating agent

The Bromölla municipality department of health care

Introduction and Rationale

The original idea for the project was raised in the municipality district nursing team. The nursing team (n = 27) wished to develop the supervisory support related to their work practice, and to improve their professional role as community nurses. Receiving a three-year systematic clinical supervision, the district nurses wanted help to move further on by the evaluation of the supervision and in developing their professional practice. As a result of the initial collaborative research work, a further research project has been developed focussing particularly on issues of interest to management within the organizations concerned.

Current Research Questions

1. What is the impact of the supervision process on community nursing practice
2. How does that impact on the way care is delivered?
3. What are the key issues that community nurses face in their current practice?
4. What is the nature of the networks that are required to deliver care to multiple chronically sick people in the community and how do the different professionals relate to each other in the delivery of care.
5. How can an integrated multi-professional care management process deliver client centred care.
6. What is the impact of an action research process on the development of new ways of approaching care.

Theoretical perspectives

Participatory approaches are becoming increasingly important in the field of health care organizations (Meyer, 2000; Springett, 2001), and many representatives of public service organizations, as for example Region Skåne, have recognized the need of inclusion of the connected peoples' involvement to ensure continual development and change. The current approach to research, in this project, is one that draws on the notion of action research as a collaborative inquiry process in which practitioners' collaboratively with the researchers, are reflecting and making research on their own practice as well as developing new ways of working and evaluating the changes they are introducing.

The introduction of basic principles of participation and equality (Socialstyrelsen, 2004), special legalization and conducted reforms (SFS, 1993: 387), national action plan (Swedish Government Bill, 1999/2000:79,) have all had an impact on health service provision. Accordingly a response to requirements to modernize health care through the development of new forms of local clinical authority, and social care as well as clinical governance has increased the level of interest in practitioner led research (Meyer, 2000; Ring, 2001).

Action research involves a cyclical process including the identification of a problem or issue, developing a plan, implementing the plan and evaluating the effects so that the new knowledge can be applied (Cornwall & Jewkes, 1995). . This characteristics and problem focused change and improvement is considered as a tool for both professional development and as an attractive option to care management (Mayer, 2000; Street & Robinson, 1995).

Implicit in this kind of research process is the willingness of practitioners to examine their own practice and make changes where appropriate (Eyck & Baum, 2002). Consequently the research process relies upon the commitment to collaboration, and voluntary and willing participation. Advocates of participatory investigations argue that it is important to involve people related to the issue in development work, and regard them as agents capable of analyzing their own situations and designing their own solutions (Cornwall & Jewkes, 1995).

In this project, the research process and practice development are intertwined. Case study (Yin, 1994), participant observation (Spradley, 1980), focus groups and the story dialogue technique (Labonte et al, 1999) are the main sources of research methodology allowing the development and application of theory directly to practice change.

Research Process

The research cycle started up with meetings with different nursing teams e.g. home care, residential care and disability services. During the initial meetings we discussed the action research philosophy and formulated a general plan comprising several action steps. It was agreed to give the working name "Omvårdnadshandledningsgrupp (OH) to this initial research group. During the research process various workshops were offered and during these activities a total of six to fourteen team members attended each time. At the general information meetings with workers across different care settings, significantly more staff attended. The steps of action and reflection offered the opportunity not only to share information, but to generate questions, stimulate discussion, check for conflicts and consensus, and to collect the data with relevance to the intended issues. The latest stage of the research phase includes fact finding and analysis, and involves exploration of ways of tackling the emerged patterns of issues. This working process generated some proposals on how to investigate the issues further. The figure below gives a summary of this process (Figure 1).

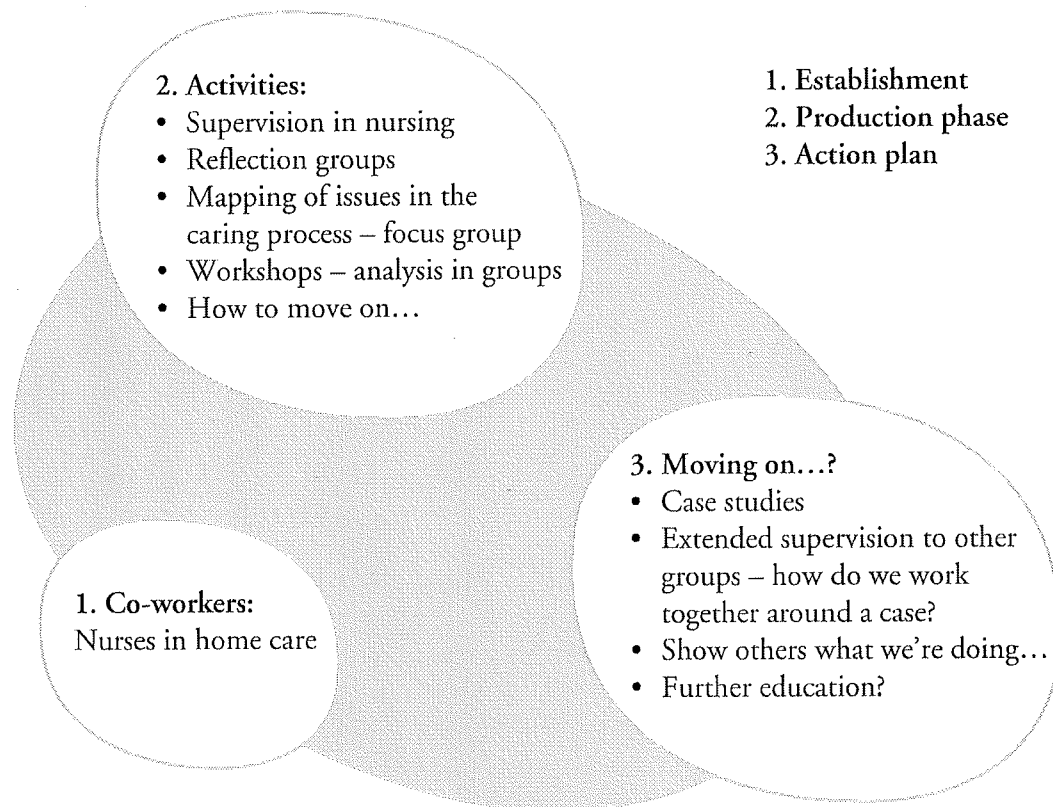


Figure 1: Application of research processes in supervising projects spring/fall 2004.

At this stage it was also considered that the enthusiasm of a new project could become dissipated if the work process did not move things forward in a systematic fashion, and if the bottom up perspective wasn't incorporated in the higher levels of the organization. This phase of the research process was the starting point for the second action research cycle.

The initial steps of the second cycle made it obvious that it was important to be clear about what the participants were trying to achieve and how it could be achieved. This resulted in meetings and involvement of managers of care units, social care authority and representatives from the central health and social care administration of the municipality.

Many meetings, involving a number of stakeholders and unit staff with the intention of discussing how best to proceed, were carried out. This second problem identification stage resulted in forming of a second research group where a team embracing different health and social care professionals could work more collaboratively and multidisciplinary, that is working client centred with integrated and coordinated care management (ISP). While the OH group interprets and decides their focus of investigation for themselves, the ISP group's focus of inquiry has been chosen by the organization. Other differences between the groups were that while the OH was an open group, it was decided that the meetings and workshops of ISP would be a closed working team, while working on the proposed inquiry. This is considered not to be a problem for any of the groups, being more or less self-contained. Even if people work with different topics of inquiry, they do not work separately across praxis, with the clients, and they probably will have influence on investigating areas of their practice. Further, to support the work of the groups, a steering group was developed. The purpose for this group work is to support the development and to coordinate activities of the OH and ISP within the organizational context.

At the present, the initial steps in the new phase of the research project are concerned with the establishment of new working groups and teams in such a way as to reflect the different research questions that have been generated. One steering group and two practitioner groups have been established. The groups all include important professional experts and decisions makers.

The steering group includes the municipally management staff, (e.g., principal from the municipally administration, förvalningschefen) staff manager of the social care board (personal chef), manager of the health care department (verksamhetschef etc). The expert groups involves staff from different disciplines e.g, district nurses, home care nurses, social workers, an occupational therapist, a physiotherapist and other staff involved in caring processes in the field. The task of the steering group is to be a dialogue partner to the researchers and to the various unit's staff involved in different organizational levels. Additionally, in dialogue with the involved stakeholders, this group will work with formulating the direction and guidelines for the project's partial goals, planning events, actions and points of departure, facilitating the involvement of staff in several action steps and coordinating the project. The task of the expert panels group is to be partners and co-researchers in the research process e.g., participate in ongoing development, designing and implementation of different steps of actions and discussions related to the staffs' members' change in their practice. The OH and ISP groups will function differently depending on the focus of their project issues.

The integrated and co-ordinated care management approach (ISP), builds on multidisciplinary teamwork and focuses on outcomes of community health and social care for the individuals receiving services and care. The job of the team members is to work from a common core of knowledge or a formal guideline, and in co-operation build up a working model for individualized health and social care. There are three aspects of the integrated care management approach. First, investigating the clients' conditions and forming the judgements of needed support (biståndsbedömning). Second, considering and finding out the appropriate support options and the third, perhaps the most difficult, is to coordinate and individualize the style of the caring support according to preferences of the client.

On the group members' initiative, in order to move the groups' processes forward, preliminary team-building workshops as participative action research activities have been developed. The workshops will include supervision with professional and managerial support as well as specific subject's seminars and methodological seminars.

Research Outcomes

The main findings: What are the key issues that community nurses face in their current practice?

Professional roles

While there is no universal definition of clinical supervision, there is a consensus that it is a practice-focused process (Barriball, While & Munch, 2004). The participants in this study reported that the supervising sessions provided opportunities to review their working problems under guidance and improve their understanding of caring situations for the benefit of client care. Working domestically and in different municipality settings, the nursing staffs' work is processed within a context, which gives a high level of individual and professional freedom and choice along with closeness to the patients or clients in environments with varying physical and social characteristics. In addition, the nurses participating in this study regarded their role as providing counselling for the client as well as for the different actors around the client, e.g., hospital staff, care staff and relatives or other involved in the provision of care. Furthermore, the nurse's role

was to act as a liaison between the different involved care providers and the client while managing medical aspects.

Challenges to practice

A number of recent policy developments have both stressed the need for collaboration and promoted different ways of working, which require collaboration (Socialstyrelsen, 2003; 2004). The analysis of empirical data has revealed that there was evidence that the nurses felt that some other of the involved caregivers did not understand their own role in the process of care. For example, there were found different approaches to care from the home care staff (hemtjänst) perspective, and nursing team. The home care services are provided and organized from above all, Socialtjänstlagens perspective, as well as arbetsmiljölagens perspective. The nursing responsibilities build on hälso- och sjukvårdlagen. When the care needed has to be provided in poor circumstances, for example when a service receiver is an elderly person living in the country side in an old cottage with insufficient sanitary conditions, there may be a different approach to manage the service. The home care staff may not be allowed to work in poor working conditions while the nursing staffs are forced to manage the medical domiciliary care just principally considering the individual care needs independently of the environmental conditions. Differences in management styles can also affect efforts to collaborate between health and social services. Divergences in professional perspectives, and disagreement between health and social services about good practice for effective treatment were regarded as a key constraint to team working.

The findings of this study must be interpreted with caution, as the study may not be representative. However, the preliminary results of this research highlights the need for caring professionals to understand each other's roles in order to ensure an appropriate, effective and client centred care. Further, this research draws attention to the need to improve team working and development of working models where the crossover between professionals may benefit service users. This is particularly important in community care where the service user is likely to be in receipt of several services. A limited awareness of the roles of others may, therefore, act as a barrier. Just as there are a number of obstacles to cooperation, a number of difficulties may also arise when seeking to implement more integrative caring initiatives.

The preliminary findings indicate that although there are some areas of differences of view depending on which level of the organization a participant is involved in, there is also a high level of consistency and agreement in perceptions of the key actions required. There is as well a strong motivation to participate in taking the research actions forward that have arisen from the inquiry process on the part of many involved stakeholders. The importance of widespread support for the project, from the top of organization as well as from the staff, has also been identified. This has resulted in requests to take forward the process with other collaborative groups.

The preliminary data analyses have illuminated a range of issues in daily work experiences faced by the nursing staff. The research points to the future development of health and social care services. Although only the first stages of the research are outlined at the present, it is considered that the action research process has offered the health care staff in the community not only the means of taking forward an idea in a purposeful way, but also the possibility to engage in further collaborative projects.

A scientific publication is planned based on the results of the first stage of the research. Abstract describing initial phases of the work have been accepted as presentation to the international health care conference, taking place in the spring 2005.

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3.6.2 Bromölla Municipality Care

The Opportunities for Patient's self-care

Suzanna Hägglöf

3.6.2 The Opportunities for Patient's self-care

- Lead Researcher: Suzanna Hägglöf
- Co-researchers: Irena Dychawy-Rosner

Reference group/participants

Staff at Hälsöringen primary care centre, Bromölla, municipality based community care and nearby care CSK.

Originating agent

Bromölla Municipality Care

Introduction and rationale

Traditional patient education is a common way to educate patients in primary care, municipality care and specialized care, and patients are often considered as passive receivers of education designed for them by health professional but not from the patient's perspectives of their needs. The research will contribute to the development of patient education from the patient's perspective in primary care, municipality care and specialized care, with a view to strengthening the possibility for self-care, as stated in Skånsk Livskraft in its advocacy of health promotion work directed to self-care. The research covers a network of care including Bromölla primary care, municipality care and in specialized care at Kristianstad Hospital (CSK).

Key research aims and objectives

The aim of the research is to examine patient education in primary care, municipality care and specialized care, and to develop contribute to the development of patient from the patient's perspectives with a view to strengthening opportunities for self-care.

Current research questions

- How do health professionals perceive their practice concerning patient education and self-care?
- What are the experiences of patient education from the patient's perspective?
- How can patient education be developed to improve self-care?

Theoretical perspectives:

The role of patient education in health care for patients with chronic conditions has been given much more attention recently, since patients in health care are being thrown upon their own resources to manage basic daily activities related to their chronic conditions (Newman et al 2004). The aim of patient education is to support and strengthen the patient's control of the disease, treatment and self-care. Self-care can be defined as the activities the individual initiates without the involvement of others to maintain their health and manage their personal needs in

the environment where they live their daily life (Klang Söderkvist & Björvell 2001). Current research shows that patient education directed to self-care in patients with chronic diseases has led to increased self-care (Sunvisson et al 2001; Monninkhof et al 2003) and also contributed to reduced costs in health care through less physicians visits (Galefoss 2003; Bhuyan 2004).

Patient education usually includes information about disease, medication, physical training, nutrition, stress management, smoking and weight. Patient education can be divided into traditional and empowerment based patient education (Moseley 2002; Pibernik-Okanovic et al 200; Skelton 1997). Traditional patient education is mostly diagnosis directed and used with chronic conditions as diabetes, heart diseases and asthma. The education usually takes place during patient's visits to a health care setting or health professionals visiting the patients in their home. Patients can be considered as passive receivers of information, which is based on the health professional's perspectives of the patients needs. (Klang Söderkvist 2001; Bhuyan 2004). The evidence for the effectiveness of traditional patient education indicates increased knowledge in patients, but increased knowledge does not necessary has impact on self-care (Wredling 1996). Self-care is often difficult to achieve, as indicated by the poor rates of adherence to treatment, reduced quality of life and poor psychological wellbeing, which are frequently reported. Self-care may not be desired by all patients. Self-care is more than simple adherence to treatment guidelines because it incorporates the psychological and social management of living with a chronic illness (Newman & Mulligan, 2004).

Empowerment based patient education is more about the relationship between patients and health professionals. Patient empowerment can be understood as a process and as a result. If the patient's perceptions and knowledge concerning their own health is taken into consideration and if health professionals focus on health as well as illness, it can empower the patients' capacity (self-efficacy) to self-care (Björvell 2001). Accordingly it is important to bring about knowledge interaction between patients and health professionals. To facilitate knowledge interaction and reflection on how behaviours, attitudes and actions can contribute to or against promoting self-care, it is important to achieve an open-minded environment that can strengthen the patient's engagement and control. The goal is to increase activity and decrease insecurity and stress of the patient to attain wellbeing and conditions for optimum self-care (Björvell 2001; Feste & Anderson 1995). Kalnins (1992) considers at least three principals of importance concerning patient empowerment:

- 1) Health promotion actions must be based on an agreement of what involved patients and health professionals consider to be of importance.
- 2) Experts and patients must work together to solve current problems and decide what needs to be done and can be done.
- 3) Health promotion actions must be according to general health policy in order to function well.

Studies (Björvell 2001; Pibernik-Okanovic 2003; Goransson, Kirkegaard & Fridlund, 2003) in empowerment based patient education in groups have shown positive results since the education has strengthen the individual, and the group by sharing participants' own experiences and through finding unconventional solutions.

Empowerment based patient education can be used in different forms, for example focus groups and self help groups, where participants tell their story how to live with a chronic disease. Several studies have shown that group discussion can contribute to improvements into daily life (Roberto & Reynolds, 2002; Thorne, Paterson, Russel 2003; Stuifbergen et al 2004). A study (Stewart & Bhagwanjee, 1999) in participatory patient education included patients who designed and led the patient education and invited health professionals as consultants. The study shows that patient led (peer-led) patient education can increase self-confidence and empowerment in patients with chronic diseases. A participatory approach emphasizes the "bottom up" approach

compared to conventional “top down” approach that treats patients as passive receiver of education designed for them by health professionals.

Milewa et al (2000) showed in their study that literature in patient education only contributed to orientate participants toward self-care to a modest extent. Several studies (Gazmararian et al 2003; Parker et al 1995) have shown that lack of literacy is not an uncommon problem and independent to related disease. The content in patient education is not described in detail that allow conclusions considering the most and least effective components which can contribute to empower the patient’s ability to take control and responsibility concerning their illness (Snoek 2003). Moreover most of education activities in clinical praxis are based on a traditional ways to educate and are not based on evaluated models of effective health care (Björk Linné 2001).

Koch and Kralik (2001) applied participatory action research approach in their study the aim of which was to examine how community nurses can assist patients living with chronic conditions to live “well”. Their findings have shown that this approach can result in changes as an effect of action at an individual level with improved self-care, and at a collective level where the PAR group instigates larger reform strategies. If health professionals can understand the process that facilitate patients to move toward incorporating chronic illness into their lives, substantial contribution to enhance chronic disease self-care management can be made.

Finding the best self-care management for chronic illnesses is imperative to deal effectively with increasing numbers of older patients with chronic illnesses and escalating costs (Newman et al, 2004). Current research indicate benefits from empowerment based patient education directed to self-care, when it comes to patients resources to self-care as well as perceived support, and reduced costs in health care through less patient visits. Skånsk Livskraft (Region Skåne 2004) advocates health promotion work directed to self-care, but traditional patient education is still a common way to educate patients in primary care, municipality care and specialized care, and regard to this background it is important to examine patient education from the patients perspectives, to strengthen the patients possibilities to self-care.

Research process

The research draws on a hermeneutical-phenomenological worldview to understand how patients act from their pre-understanding of their meaning and situation. The design of the research is qualitative, using interviews and focus groups to capture experiences of patient education and self-care from the patient’s perspectives. PAR research emphasizes dynamic approaches to investigation that are reflective, participatory, cyclical, focused on understanding, change-oriented and community-oriented. The empowerment strategies are characterized by information and feedback, relationships, decision-making and consciousness raising: It requires participants to acquire and share information. It builds relationships both internally within the primary group and externally. Participants control decision-making through their participation in research design. Consumers build a broader awareness of factors affecting their health through the learning components of PAR (Stringer & Genat, 2004).

In PAR the detailed content and direction of a research project cannot often to be determined at the outset. These take on a definite shape as the work progresses and are kept continuously under review. The research activity is presented as a cycle of problem identification or situation analysis, planning events, action and evaluation which may lead to identification of new problems, planning events, action and evaluation (Waterman et al., 2001). Validity in PAR is achieved by establishing trustworthiness (Stringer, 2004). Trustworthiness involves procedures for attaining *credibility* (the plausibility and integrity of a study), *transferability* (whether results might be applied to other contexts the research setting), *dependability* (where research processes

are clearly defined and open to scrutiny) and *confirmability* (where the outcomes of the study are demonstrably drawn from the data).

An initial scoping exercise was undertaken to ascertain current approaches to patient education and determine the level of interest in the topic amongst key persons in primary care, municipality care and the Diabetes reception in specialized care. Telephone interviews were undertaken with a representative sample of staff. This included primary care (n=16), municipality care (n=5) and in specialized care (n=5).

This identified the issues currently facing these sectors, which are:

- Increasing number of patients with neck- and shoulder pain
- Increasing number of patients with fatigue syndrome
- Needs for problem based learning in patient education
- Evaluation concerning patient's needs for glucose monitors in patients with diabetes is of interest due to high costs
- Development of patient education with focus on patient's capacity, attitudes and behaviour is crucial
- Positive experiences of patient group education
- Needs for education and information concerning how to communicate with patients concerning patient education
- Collaboration between primary care, municipality care and specialized care concerning patient education is of importance to develop
- Need for time to reflect

Future research

It is expected that the next phase of the research will explore the patients' experience of patient education and self-care in primary care, municipality care and specialized care, and examine how patients act from their pre-understanding of the meaning of patient education and its context. Data collection will be in the form of individual in depth interviews and focus groups interviews with patients. This will be followed by an interactive workshop with patients and health professionals in focus groups with a view to examining the ways in which patient education can be developed from the patient's perspective. This may lead to specific interventions within primary care, municipality care and specialized care. Finally the impact of the changes made to patient education as the result of this process will be evaluated using a variety of data collection methods.

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Appendix 1

Research principles and basic values for the research platform for Närsjukvård (English version revised 041203)

1. Individuals and groups

The research within the platform is concerned with research areas within health and social everyday work that are urgent for the *immediate/nearby surrounding/neighbouring* society. The projects are governed by a research approach *directed towards the whole*, through creating conditions for *knowledge development, active participation* and *development work* for practitioners. The initiative to research comes from the people wanting an issue to be examined. The research includes the participating individuals and the group throughout the entire project.

2. The research process

The research process is governed by practical and *action directed* everyday research where *the dialogue* and *involvement* of various actors plays a decisive role for the course of action and as a creative tool to work with, where the *role of the researcher* is one of consultation as well as a entrepreneur and a process leader.

Through the encouragement and promotion of *learning* about the issue in focus, a *knowledge growth* is taking place. The aim is a *democratic* group learning culture, in which emphasis is being put on *variety* (diversity, pluralism) and on *openness* towards other perspectives.

The *genuine dialogue* is at the core of the process: "A dialogue can be seen as a platform – a plaza – i.e., an open space for an exchange of ideas and a process where we examine our thoughts in order to better understand their content." (Karlsson 2001:211). In the dialogue, learning as both teaching and training (learning) is taking place, the individuals are teaching each other and from each other and in this way contributes to a mutual construction of knowledge.

Reflection is the mechanism through which the individuals learn for their actions. They reflect individually and together, in the setting of both their own preconceptions (pre-understandings) and the other group member's contribution of thoughts and experiences. Between the reflection and the action, a dialectic movement arises and continues throughout the change process. Through the great variety of interpretations and perspectives that are generated, the group reaches, through dialogue, a mutual interpretation; *consensus*.

3. Objectives

The purpose of the research is to contribute to *theory and method development* by applying the prerequisites for *democratic* forms of critical examination and the participants' possibility to *influence, design, learn and implement* change in praxis through this.

The aim of the research is to generate new *knowledge* leading to *change* of a social issue or other area of interest. The individuals (stakeholders) affected by the issue, participate together in their own change process. The role of the researcher is one of a *guide*.

The purpose of the research is an agreement between the individual, the group and the researcher/s. The research includes and shall be acknowledged in all by the individual and the group:

- in the formulation of the problem
- in the planning and realization of the project
- in identifying and choosing data methods
- in the data collection process
- in the process of analysis and summary of results
- in documentation and presentation
- the participants and the researcher/s together owns the result of the research

4. Change

The research within the platform is based on methodological approaches where organizations, staff and users through dialogue and influence take an active part in creating knowledge and investigation activities. The developed knowledge will be further used within the practical developmental work within steering and development of the public services within health and social care.

Appendix 2

Seminars and conferences attended by Forskningsplattformen

To support the development of the platform, a series of seminars has been carried out during the academic year. This includes internal as well as external guests.

Seminar themes 2004

- Action Research for Organizational Development (Dr Tony Huzzard, LU)
- Complexity in systems (Sören Augustinsson, BET, HKR)
- Dialogue around the common issues and research questions
- Patient/client centred care – what does it mean?
- Qualitative Methods (Malin Åkerström, LU)
- How do people talk a about Närsjukvård – a preliminary review
- Organisation change in psychiatric care, research connected with the platform (Ann-Marie Ek, PhD, LU)
- Experiences of participative and action based research (Kerstin Blomqvist, HV, HKR)

FPL Internal All-Days 2004

- 11/5 Dialogue Day. FPL staff and coordination group on Närsjukvård, action research, continued communication and the notion of a platform.
- 24/8 FPL internal all-day. Dialogue on common research themes and issues

Conferences and events attended by platform staff 2004

- “Quality in Qualitative Research” The 3rd Nordic interdisciplinary conference on qualitative methods in the service of health. University of Aarhus, DK May 5-7 2004
- “Providing integrated health and social care for older persons – Facing the challenges in Europe”. European Centre for Social Welfare Policy and Research and PROCARE, Venice, Italy, October 21-23 2004

- “Hälsoforum för Patientutbildning”. KS, Stockholm 26 november 2004
- ”Power, knowledge and learning”, SVUF's (Svenska utvärderingsföreningen) 1st conference. Norra Latin, Stockholm, April 22nd -23rd 2004

Appendix 3

The platform Team at Högskolan Kristianstad

Jane Springett	Visiting Professor	public health
Marie Nilsson	project assistant	
Sara Sätersten Haraldsson	coordinator/secretary	
Leif Karlsson	Senior researcher	public health
Agneta Abrahamsson	Senior researcher	public health
Birgitta Höglund	Senior researcher	social work
Sven-Erik Olsson	Senior researcher	social work
Irena Dychawy-Rosner	Senior researcher	social work
Lisbeth Lindell	Senior researcher	nursing
Lena Persson	Senior researcher	nursing
Kerstin Blomqvist	Senior researcher	nursing
Agneta Berg	Senior researcher	nursing
Lena Wierup	Researcher	nursing
<u>Yvonne Johansson</u>	post graduate student	social work
<u>Cecilia Lindskov</u>	post graduate student	social work
<u>Ingela Olsson</u>	post graduate student	social work
<u>Pia Petersson</u>	post graduate student	nursing
<u>Suzanna Hägglöf</u>	post graduate student	nursing

Appendix 4

List of scientific publications of staff associated with the platform

Agneta Abrahamsson

Abrahamsson A, Springett J, Karlsson L, Ottosson T. Making sense of the challenge of smoking cessation during pregnancy. A phenomenographic approach. In press 2004: Health Education Research. doi:10.1093/her/cyg127

Abrahamsson A, Springett J, Karlsson L, Håkansson A, Ottosson T. How smoking cessation in antenatal care: Some lessons from Swedish midwives' experiences of approaching women smokers in antenatal care (Midwifery. Accepted)

Agneta Berg

Benzein E., Berg A. The level of and relation between hope, hopelessness and fatigue in patients and family members in palliative care. *Scandinavian Journal of Caring Sciences*, Accepted.

Clausson E., Pettersson K. Berg A. Schoolchildren's Health – Experienced by the School Nurses. Submitted.

Lindh I-B., Severinsson E., Berg A. Nurse students view of moral responsibility in nursing. Manus.

Kisthinos M., Berg A. Theoretical perspective in clinical supervision in nursing. Manus.

Kerstin Blomqvist

Blomqvist, K. *Prioriteringar i vårdflöden för äldre – en förstudie*. (2004). Rapport 2004:5. Prioriteringscentrum.

Borg, C., Hallberg, IR., Blomqvist, K. (submitted). Life satisfaction and wellbeing among informal caregivers in comparison with non-caregivers.

Books and chapters:

Blomqvist K. & Edberg A-K. (red., 2004). *Att vara och att vårda äldre*. Lund, Studentlitteratur.

Blomqvist, K. Vardaglig smärta. I Blomqvist K & Edberg A-K. (red., 2004) *Att vara och att vårda äldre*. Lund, Studentlitteratur.

Blomqvist K. & Hellström Y. Att ta emot hjälp. I Blomqvist K & Edberg A-K. (red., 2004) *Att vara och att vårda äldre*. Lund, Studentlitteratur.

Yvonne Johansson

Edén L, Andersson IH, Ejlerthsson G, Ekström BI, Johansson Y, Leden I, Petersson J. Return to work still possible after several years as a disability pensioner due to musculoskeletal disorders.

A population based study after a new legislation in Sweden permitting "Resting disability pension" (accepted 2004).

Leif Karlsson

Abrahamsson A, Springett J, Karlsson L, Ottosson T. Making sense of the challenge of smoking cessation during pregnancy. A phenomenographic approach. In press 2004: *Health Education Research*. 2004; doi:10.1093/her/cyg127.

Abrahamsson A, Springett J, Karlsson L, Håkansson A, Ottosson T. How midwives approach smoking cessation in antenatal care: Some lessons to learn from Swedish experiences. (Accepted: *Midwifery*).

Lena Persson

Glimelius Petersson C. Persson L. Sjuksköterskors registrering av vårdtyngd på en intensivvårdsavdelning – en undersökning av instrumentets validitet och reliabilitet. (accepted *Vård i Norden*)

Persson L. Hallberg IR. Lived experience of survivors of leukaemia or malignant lymphoma. *Cancer Nursing* 2004; 4 (27): 303-313. Svensk Sjuksköterskeförening, Omvårdnad som akademiskt ämne. Närståendes behov. Medförfattare.

Jane Springett

J: Springett (in press) Geographical Approaches to the Integration of health promotion in health systems, a comparative study of two health action zones in the UK — International Journal of Health Promotion and Education

Abrahamsson A, Springett J, Leif Karlsson, Ottosson T (in press) Making Sense of the Challenge of Smoking Cessation during Pregnancy: A Phenomenographic Approach Health Education Research

Abrahamsson A Springett J Karlsson L Håkansson A, Ottosson T, (in press) How midwives approach smoking cessation in the antenatal care: Some lessons to learn from Swedish experiences Midwifery

Porcellato, L., Dugill, L. and Springett, J. (in press) A Longitudinal Study Exploring Primary Schoolchildren's Perspectives on Smoking: Results from the Early Years Phase. Childhood Studies

Woods S Springett, J Porcellato L and Dugill L (in press) " Stop it, its bad for you and me " Experiences of and views on passive smoking among primary school children in Liverpool" Health Education Research

The following is under review :

Mair M, Barlow A, Woods S.E., Kierans C, Milton B, Porcellato L, Springett J, and Dugill L (under review) Lies, Damned Lies and Statistics? Reliability and personal accounts of smoking among young people Social Science and Medicine