A New Care Concept -

Making Collaborative Home Care Work

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Abstract In this paper we discuss the fact that more and more patients are treated in their homes by a whole set of organizations, sometimes with different ownership, and how this fact places new and heavy demands on health care and home service staff to communicate and to collaborate. We further discuss the need for communication and collaboration on different managerial and operational levels. In particular we point to the need for managers in different organizations to agree on ways of communicating and collaborating on the operational level and that this aspect has to be taken into account during procurement of home care services. As a result the paper suggests a number of methodological measures and IT solutions to support organizational development, coordination and collaboration.

Keywords

Collaboration, home care, home health care, home service, IT support

1. Introduction

Health care in Sweden is currently in a phase of great change. One important change concerns the fact that more and more patients are treated and taken care of in their own homes instead of in hospitals. This includes also severely ill patients, for whom several different professions from health and social care may be involved in the care process. In order for the patient to get good total care, this poses essential demands on collaboration, cooperation and coordination among the involved care givers. The situation gets more complicated due to the fact that the many different professions involved belong to different organizational units and often with different owners, private, county councils or municipalities.

In a previous paper [1], we have accounted for an investigation among two Swedish communities, Stockholm and Umeå. The results here indicate that there are indeed problems when it comes to inter-organizational communication and cooperation in home health and social care. Most of these problems have to do with lack of information exchange among the various units and individuals involved. In two subsequent papers [2,

22] we have analyzed the requirements this poses on collaboration and coordination. The findings stress the need for collaboration among both managers at the strategical and tactical levels and staff at the operational level, in order to facilitate and ensure a high-quality care for the patient. In particular managers of different organizations need to collaborate in order to set up goals and routines for collaboration at the operational level. Collaboration also has to be taken into account during procurement of health care and home services.

The aim of this paper is to further study various issues that have to do with collaboration among different health care and home service units and professions, in order to come up with organizational and/or IT-based solutions. This involves identifying the need for new ways of working, for pointing out responsibility, and for mobile and immediate access to information concerning both medical records and administrative data. The analysis is based on a patient and process oriented perspective.

In the following we define how we use certain terms in this paper. Although admittedly a bit vague, the definitions will hopefully help to make the paper easier to understand.

- social care (sometimes denoted as home service) to denote the personal care that involves help with cleaning, shopping, providing food and personal care such as help with outdoor activities or personal hygiene. This kind of care is, in Sweden, the responsibility of the municipalities. It may be provided by one of their own units or by some private company that has a contract with the municipality.
- home health care that may involve
 - o basic home health care provided by nurses and nurse's aides and which is in many cases the responsibility of municipalities but sometimes is outsourced to the primary care run by the county councils.
 - o advanced home health care provided by teams of doctors, nurses and other staff and operated by the county councils. This care often concerns severely ill children or patients in palliative care.
- health care and home services (sometimes denoted health and social care or just home care) to denote the total care conducted by home service and home health care units.
- patient care process to denote the sequence of treatments and other activities performed by health or social care personnel for the patient and in which the patient and often his relatives participate.

To these 'definitions' we would like to add the "new care concept" to denote a setup of care services performed by a set of care providing units. This new concept denotes a holistic view of the care and services given to a person from a patient perspective, where the patient does not see the border between different care giving units. The new care concept comprises a coherent set of activity types aimed at meeting a need for a group of patients. Structured collaboration between the care providing units is a prerequisite. The new care concept builds on procedures, routines and rules for communicating and coordinating activities in order to achieve a better collaboration. The "new care concept" must be based on a clearly stated care strategy, and define how care should be conducted collaboratively and in the best interest of the patient. For every single patient, a care plan should be laid out with clearly formulated goals. Ideally goals should be connected to plans for actions to achieve the goals and also consider effects of chosen actions on economy (the units and also what lack of quality caused by the wrong or not adequate

actions might cost) and the staff's working environment. The responsibility for coordination and collaboration should be pointed out and distributed among the different actors taking part in the care activities. One of the largest problems is to clarify the tasks included and how different types of competencies and units are used collaboratively in different phases of the patient process. Clarifying and explaining the "new care concept" for both care personnel and patients and their relatives is therefore important.

The paper is structured in the following way: The next section discusses briefly the notion of collaboration and the various forces influencing collaborative. It will also account for some related research. Section 3 discusses the need for communication and collaboration on different managerial and operational levels. In Section 4 we we discuss what kind of methodological, organizational and informational support will be needed to support collaboration in home care. Finally, in Section 5 a few concluding remarks will be given. For simplicity, we use, where needed, "he" and "his" to refer to the patient, although he may be of either sex.

2. Collaborative home care

Two or more parties collaborate when they work together in order to achieve a mutual goal, i.e. perform a task that each one cannot cope with alone or at least not as well or at as low a cost. This implies first of all that the mutual goal must be understood by all parties. They have to understand the basic circumstances, demands and restrictions that the other part faces. Each party must also be clear about how the work procedures and tasks are distributed and how one's own work contributes to the common goal.

Thus, collaboration between organizations is a complex matter and existing research has focused on a wide variety of aspects. In research concerning collaboration within health care, van Eyk and Baum [3] have studied what they name as interagency collaboration. Hudson [4] has studied joint commissioning across the primary health care-social care boundary in the UK. El-Ansari et al. [5] have focused on public health nurses' perspectives on collaborative partnerships in South Africa. El-Ansari et al. [6] investigated collaboration and partnership and the problems with measuring collaborative outcome. Lichtenstein et al. [7] have studied the effect status difference has on individual members in cross-functional teams. However, few of these studies have focused on mobile home-based health care and its specific needs.

It is also possible to find some research in the field of mobile work and information processing. In the health care area, Ammenwerth at al. [8] explore how mobile artifacts can be used for information processing in a hospital. Pascoe [9] describes how mobile artifacts increase the amount and speed of data being recorded out in the field; Najjar et al. [10] describe how wearable computers might increase the performance of quality assurance inspectors. Guerlain et al. [11] write about personal information systems for roving industrial field operators and Heath and Luff [12] examine the ways in which mobility is critical for collaborative work.

Figure 1 depicts some of the forces that influence how collaborative care should and could work and hence how the "new care concept" ought to be designed. Each of these stakeholders has its own requirements that need to be taken into account such as to reach a reasonable compromise that meets most requirements at the same time as it focuses on the best interest of the patient.

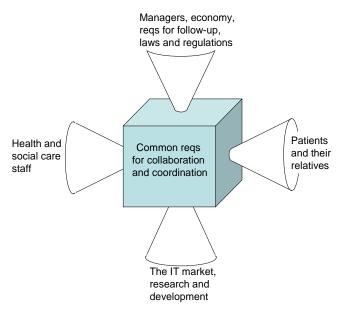


Fig 1. Stakeholders influencing collaborative care.

It is obvious that different collaborating parties have different responsibilities and demands as well as different aims and preconceptions about the collaboration. For collaboration to work, the parties have to communicate

- over a distance, i.e. the communicating parties are at different locations and have to use some kind of tool to bridge that distance, or
- over time, i.e. a place (a database) is needed, where information can be stored on one occasion and picked up and read at a later time.

When several parties collaborate it is often difficult to formulate one single objective, since each organization has its own goals. It is, however, important that all involved are aware of the overall purpose of the work around an individual patient and make sure that this is in accordance with their own and with the patient's goals.

A simple example of collaboration is a doctor in primary care who needs to consult a specialist in a hospital. A more complex case is when a patient's problem and its treatment require many units and individuals to be involved. An even more complicated case arises when several care units and professions are involved and where the patient suffers from several diseases. This kind of case is not uncommon e.g. in palliative care.

To conclude, cooperation between different health and social care units as well as patients and their relatives is crucial for achieving good quality in the collective care effort around the patient and also to make the total utilization of resources as efficient as possible. It should also be stressed that the patient himself and his relatives are part of that cooperation.

3. Collaborating on different organizational levels

Collaboration may take place both at a strategic and a middle (tactical) management level and at the operational level among the staff carrying out the care. These levels exist within all health and home service organizations. Thus, there are several organizations and organizational levels each one of which is responsible for its part of the total care provided for the patient. Cooperation can hence be understood both from a strategic/tactical and from an operational perspective. Fig 2 shows that at least 7 different paths of communication are needed.

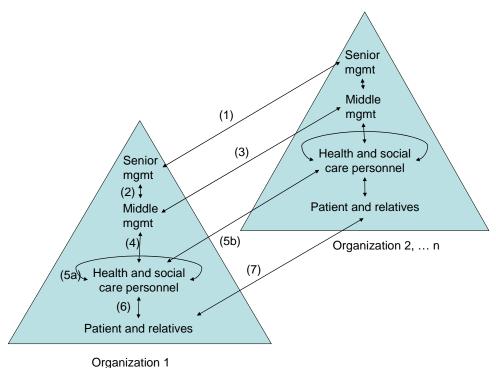


Fig 2. "Levels" of cooperation in home care.

Fig 2 shows where both vertical and horizontal intra and inter organizational coordination is needed, which is in line with complex organizations' continuous needs for both specialization and integration stressing the importance for coordination [15]. More specifically communication, collaboration is needed or desired (see Figure 2):

- 1. Among top management to agree on goals, objectives and general level of collaboration.
- 2. Between senior and middle management in different organizations. At top levels one need to agree on strategy and policy for distribution of responsibility. At the tactical level an agreement is needed on routines and rules for how cooperation is to be achieved.
- 3. Among managers at the middle level, e.g. between same type of managers in order to design collaboration structures, between procurer and producer in order to agree on terms for the delivery of care services.
- 4. Between managers and the operational staff. Knowledge of strategy, policy and routines need to be conveyed to the care personnel.
- 5. Among operational staff: Those who work with a patient need to exchange information about treatments and other activities that have been carried out, changes in plans, changes in the patient's situation etc.
 - a. Between different individuals and professions at the operational level within the same unit.
 - b. Between different individuals and professions in different units. This staff need to coordinate health and social care both on an immediate and a long term perspective.

- 6. Between care personnel on one hand and the patient and his relatives on the other. Care staff needs to inform the patient and his relatives about plans both in a short and a long term perspective, as well as changes to the plans.
- 7. Between patients and between relatives e.g. in supportive patient's associations. Such can be of great help to make the patient and the relative understand the illness, its treatment, its consequences, and how it is possible to live with it.

As mentioned, collaboration may also take place among people from different units, e.g. health care personnel from a health unit may need to collaborate with personnel from the municipal home service (5b in Figure 1) and staff from e.g. primary care. Note that this also indicates that there has to be a working communication of policies and guidelines from their respective managers (4 in Figure 1). Managers in both organizations need to decide how they want to organize the cooperation and how it will be accomplished at the operational level.

Managers of today are more aware of the need of a working information infrastructure. They are, hence, aware of the need for more knowledge when it comes to what kind of information they need and how information can be made available in order to bring about an effective communication around and with the patient. It is a common situation that different parties are responsible for different tasks, i.e. responsible for different sub-goals of the overall goal. The main organizational problem is for both parties to agree on a holistic view of the care process and the different stakeholders roles, tasks and restrictions.

A patient in home health care usually meets a set of persons perhaps from different care providing organizations that they experience as a team. However, these teams are seldom formally set up but simply appear as a result of different organizations taking on different duties. Often the various actors around a patient have very limited knowledge of which other organizations, individuals and professions are involved. Sometimes they meet in the patient's home and because of that may acquire knowledge of each others existence and role. In other words, there is usually not much organized collaboration between people from different organizations, which makes it difficult to arrange good collaboration that centers on the patient's needs and well-being.

4. Need for organizational development and IT support

For IT support to work it is necessary for various actors involved in the care around a patient to have a reasonably common understanding of the meaning of terms and concepts they have to communicate. Unclear or ambiguous concepts are a problem in the whole health care sector. Here, like in other parts of society it is not rare that even the most central terms are understood differently among different stakeholders. We believe that to a certain extent this is something one has to accept and learn to live with, but at least we need to be aware of it. In the discussed context it is, however, desirable to agree at least on terms and concepts that concern collaboration. The models, primarily information models that have been developed in the projects InterCare [17, 18], Sams[19, 20] and MobiSams [21] are important contributions to this issue. These models build on a process that describes important information exchanges around the patient regardless of which organization is responsible for the information.

Ideally, all involved should have access to Internet by means of the usual tools such as web browsers and e-mail. To this one may add synchronous and asynchronous tele conferencing tools that may help people to meet or consult with each other without having to travel physically. It is necessary that all involved get an understanding for each others tasks. This can be accomplished by means of regular training and also by means of common meetings and workshops that gather representatives on different levels and of different organizations.

In the following we will provide a brief discussion of which more specific types of support may be needed at each level.

1) Senior management

Senior management will need to physically meet in order to get to know each other and to discuss informally what is needed in order to bring about fruitful collaboration. Probably, also representatives for middle management and operational staff should take part in these meetings. In addition they all would utilize the normal kinds of communication media such as telephone, fax and e-mail. "Meetings" may also be organized by means of synchronous and asynchronous conferencing systems.

In order to clearly state goals and policies methodological help such as modeling sessions lead by skilled facilitators is needed. Suitable templates may be set up to formulate the goals and policies. Various other means such as learning materials could be used to disseminate the result among those concerned.

To achieve collaboration and coordination it is important to jointly achieve a common mental model over the core problem and the optimal core process on all levels and agree on an agenda for implementing and adjusting the optimal care process to suit all stakeholders, including the most important – the patient. It is the responsibility of senior management to ensure that such a common mental model is achieved.

2) Senior to middle management

Overall goals and requirements need to be conveyed to and agreed among middle management. Requirements need to be further refined such that demands for routines, methods, templates and other tools are clarified.

For this the top and middle management need to meet. They also need help from requirements experts as well as methodological support such as various tools for modeling, designing and describing routines and processes.

3) Middle management to middle management

Routines, methods, templates need to be developed for

- how to state and express quality requirements. Devising means for how they should be measured in a way that it becomes part of the normal way of working.
- how to take collaboration into account already during procurement. For this to work both procurer and producer need to agree.
- how to design routines for collaboration and, in that context, how to utilize IT support for communication and collaboration between units on the operational level.

For this the managers need help from experts as well as various tools for modeling, designing and describing routines and processes.

4) Management to operational staff

Methodological support is needed for managers and operational level experts to help them build the necessary routines for how to collaborate on the operational level. They also need means to disseminate decisions and to implement routines and to make operational staff understand how they should best utilize communication, coordination and collaboration tools.

5) Between operational staff within same organization or in different organizations

The research projects Sams, Intercare and MobiSams have resulted in explicit knowledge on how improved and patient-centered collaboration among care providers can be accomplished. The improvements partly build on an enhanced way of working and partly on a utilization of IT support that aims at strengthening collaboration. The new ways of working should be described in process and conceptual models, which will also function as the basis for building the IT support. The MobiSams project has also had the intention to clarify the patient's own process, i.e. on one hand how it functions today and how the patient experiences it, but also how it would appear should the suggested new ways of working and the IT tools be functioning.

The IT support developed in MobiSams comprises a set of services that are well defined and built for communication. They are able to exchange information in a structured way. The services presently available at concern:

- 1. Planning and coordination of the individual care process as a whole. This would include formulation of goals and objectives.
- 2. Allocation of tasks and resources. Clarification of the personal responsibility for achieving goals and objectives for each task. How goal fulfillment should be measured.
- 3. Planning and registration of care activities.
- 4. Registration of undertaken care activities. This should be done in such a way that goal fulfillment can somehow be measured.
- 5. Follow up and evaluation of the care process

The MobiSams project has implemented these tools in a test-bed where they can be tested together with new ICT techniques such as mobile and handheld devices. The project and test-bed were set up to work such as to facilitate learning while developing the "new care concept" as an enterprise including the ways of utilizing IT. Organizations and individuals that possess knowledge about adequate platforms, architecture, network and mobility technique that are suitable for making the applications useful in the care process have been participating in the work with the test-bed

It has also proved to be very useful to have web-based knowledge management tools [Eklar] for expert doctors and nurses to share knowledge and experience with field workers in home health care.

6) Between operational staff and patient/relatives

First of all, the patient and/or his relatives should have access to his own care plan and diary. To some extent the patient ought also to have access to his medical record. Exactly

what information, if any, the patient should be authorized to see or possibly change might be decided in each separate case, provided this does not lead to too much administration.

Tele conferencing tools for communication between patient and care giver has a great potential for reducing the number of patient visits to primary care or hospital and to make patients and relatives feel more safe [23].

Last but not least useful information for interested patients can be disseminated via the web. Such dissemination can take place on the initiative by e.g. particular clinics or patients organizations such as American Diabetes Association (see http://www.diabetes.org/home.jsp). These association may also provide tools for patients to monitor themselves and their disease.

7) Among patients/relatives

As mentioned above, patients organizations can play an important role in spreading knowledge and experience among patients and their relatives either by the web or by means of other physical or electronic channels. They may also provide for where patients can meet to share experience. Nowadays there are also private "blogs" where particular patients or e.g. relatives of severely ill children share their feelings.

5. Conclusion

In this paper we have discussed how the fact that more and more patients are treated in their home by a whole set of people from different organizations places new and complex demands on the communication and collaboration among health care and home service staff. We have further discussed the need for communication, collaboration and coordination on different organizational levels, i.e. managerial and operational levels. In particular we have pointed to the need for organizational development and for IT support. More precisely we suggest that

- there is a clear need for methodological help and IT support for managers. They need both to formulate and refine goals for collaboration and design work routines for collaboration when comes to procurement of health care and social services as well as for collaboration at the operational level.
- video- and teleconferencing may be useful for collaboration both between managers and operational personnel and for communication between patients or their relatives and healthcare staff.
- there is a need for specialized software for collaboration and coordination at the operational level. This software needs to provide both access to medical information for those that are authorized and administrative support to help coordinate the daily work of both health care and social service personnel.

We need, however, to delve deeper into the precise requirements for methodological and IT support at various levels. Among the issues that remain to be addressed in depth it is worth mentioning how to state and measure quality requirements when it comes to health and social care.

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