

Specialized palliative home care in Sweden with special respect to the development in sparsely populated areas

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This study describes the early development of specialized palliative home care in Sweden. Examples from northern Sweden are presented where the catchment areas extend beyond 30 minutes travelling time. The key elements in sparsely populated areas are collaboration with local district nurses and general practitioners and proactive planning for emergencies that may occur. These plans include informative dialogue with patients, their families, as well as locally involved staff. The challenge for specialized palliative medicine is to be available to everyone in need regardless of distances, site of care, and diagnosis.

History

Before modern medicine developed, palliative care at home was frequently the only care available. During the 20th century, medical progress emerged with such stunning speed that by the 1960s people almost had forgotten that many people still died from incurable diseases. In 1962 in Linköping, Sweden, Per Arnander organised the first palliative home care in Sweden. He gave it the name LAH (Hospital Attached Home Care) and stressed the importance of 24-hour availability of both nurses and doctors.

When Barbro Beck-Friis, a geriatrician in Motala 30 km west of Linköping, launched her LAH project in 1977, the concept further stressed that incurably ill persons needed a multi professional

team to provide intensive care 24-hours a day even if the patients were in their own homes. According to this project, attending doctors and nurses were required to reach a patient's home within 30 minutes, i.e. an operating radius of 30-40 kilometres. Through decisive and inspiring leadership based on ethical principles that all humans should be equally valued and respected, especially for their autonomy and integrity, she spread this model of care all over the county of Östergötland. Another strong argument for the spread of this care model was the cost savings due to the use of fewer hospital days (1). During the early 1980s, similar units appeared elsewhere, e.g., in Örebro, Ersta, and Nacka. The Nacka unit was the first unit with an organizational ba-

sis in general practise.

During the 1990s, we saw a substantial increase of these units all over Sweden: SAH (hospital or nursing home attached home care); MOH (medically extensive home care); KVH (complicated care at home); AHS (advance home care); PAH (primary care attached home care); and ASiH (advanced care at home). The diversity of these units illustrates the ad hoc processes that generated these units. Typically, the impetus for establishing these types of units was provided by one or more dedicated care professionals and/or a local politician. Any kind of local or even more regional or national infrastructure was completely absent, with the exception of the units established in Östergötland, the cradle of Swedish palliative home care.

The vast majority of these initiatives, i.e., palliative home care teams, loyally adhered to the principles outlined by Barbro Beck-Friis, who in 1993 presented her PhD thesis on this topic. Her thesis stressed the high degree of satisfaction among spouses and staff working in palliative home care as well as the favourable economic outcomes generated by this organizational set up (2).

Palliative home care in sparsely populated areas

During the early 1990s, other home care units appeared in more sparsely populated areas in the northern cities of Östersund (Storsjögläntan) and Skellefteå (AHS VIOOL). Both these

units were based at the local hospitals, but their catchment areas consisted of relatively few inhabitants (126 000 and 72 000, respectively) spread over areas extending beyond the earlier fixed maximum radius of 30-40 kilometres. This situation raised questions of equal availability of care, as all inhabitants pay the same percentage of tax on their incomes regardless of where they live in relation to the local hospital. In the catchment area for Östersund, only 60% of the population lived within the stipulated 30-minute radius. Involved palliative professionals in these rural areas all agreed on the principles of equal availability regardless of place of residence and that the need of and wish for palliative home care is likely to be similar in all geographical areas. This assumption reflects conclusions formed by several international studies: 50-60% of persons with incurable disease prefer to be cared for at home (3,4).

Based on these assumptions, in the early 1990s both these teams started to develop a local concept of palliative home care suitable to their local conditions. As the team in Östersund has a catchment area of 44 000 square kilometres with one-way driving distances between 100 and 250 kilometres, it was evident that the way to organize the daily work of the team had to include tight collaboration with local care professionals. The established standard elsewhere in the country was that the palliative home care team itself supplied all professional support needed 24 hours per day including physicians, nurses, auxiliary nurses, social workers,

physiotherapists, and occupational therapists. This organizational set up was not possible for Östersund.

The Östersund palliative home care team even today only works during traditional office hours Monday through Friday. The rest of the hours are covered by district nurses on call covering the whole catchment area. If a physician is needed after office hours, GPs are on call until 9 p.m.; thereafter, all contacts are directed to the emergency ward at the hospital. This structure emphasizes the need of proactive planning by the team in collaboration with locally responsible district nurses. These patients need to have their prescriptions and other required drugs available at their home. In addition, caregivers need a means of ensuring that care goals are communicated accurately. If the patient needs hospital care, they can contact their "home ward" at the hospital directly. Most of the time they can get a bed on the ward directly after a ward nurse approves the request. The doctor on call is contacted upon the patient's arrival and will examine the patient as soon as possible on the ward. This routine saves the patient the ordeal of prolonged waiting in the emergency ward. If an incurable patient who is cared for by the palliative home care team has decided (often in conversations with their spouse, family, and district nurse) that they need to go to the hospital, emergency physicians will respect their request. These patients may need to be admitted for medical or psycho-social reasons.

Since the late 1990s, this model has

been used in the Östersund catchment area (i.e., the whole county of Jamtland). The proportion of home deaths among these patients has slowly increased to about 60 to 70% annually. The remainder is equally divided between death at hospital and in local nursing homes. Median time supported by the palliative team is 45-60 days with a range between one day and two years and 90% of the diagnoses are cancer.

During the same period, the team in Skellefteå developed a 24-hour service covering the hospital's catchment area (i. e., a radius of 35 to 90 kilometres). They managed their out-of-office coverage by incorporating the district nurse's on-call organization in their team. The specialized team is available 24 hours per day seven days per week. Notably, the vast majority of patients live within the stipulated travel distance of 30-40 kilometres from the hospital.

These different solutions illustrate a creative process aimed at solving the needs of palliative care at home in a way that suits the local conditions. The core issue to the patient and their families is that they can attain the professional support they need. Administrative issues such as which professionals belong to which organizations are completely without relevance to the patients as long as they know how to access help when the need arises and that they feel confident that their requests will be handled promptly with skill and empathy. The key issue for the professionals involved is a mutually respectful cooperation including frequent exchange of information,

proactive information to the patient and their relatives, and a generous exchange of experiences and knowledge.

By the end of the 1990s, four of 21 counties (Stockholm, Östergötland, Kalmar, and Jamtland) in Sweden had developed their palliative home care teams to the extent that they covered the whole county. This development has continued during the 2000s. The first national standard for palliative care was published this spring (5). The still existing white spots on the map (representing the extent of palliative home care coverage) are gradually disappearing. Fewer and fewer palliative home care teams remain that exclusively offer their services to patients with cancer diagnoses. They have been replaced by teams that base admission decisions on the genuine needs of the incurable patient irrespective of their diagnosis.

Recently, other initiatives in sparsely populated areas of northern Sweden have emerged in the counties of Västerbotten and Norrbotten. Both these initiatives are based on a consultative approach supporting existing GPs and district nurses.

Looking ahead

The national standard for palliative care (5) clearly identifies the remaining steps needed to ensure that every incurable patient receives palliative care according to his or her individual needs. Accordingly, palliative home care has to be available to all regardless of diagnosis, location of residence, and level of care. It is distinctly decla-

red that general palliative care has to be available in all care institutions in Sweden based on the competence of all care personnel. To enable this basic provision, a conscious emphasis needs to be placed on teaching general palliative care in all care fields.

When the capacity of the local care team (e.g., GP and district nurse or surgeon and ward team) reaches its limits and is not capable to palliate the suffering of their patients, a specialized consultative team needs to be included in the treatment plans. These palliative consultative teams have been completely non-existent in Sweden until now. The raw model is the British system of hospital-based palliative care teams (without beds) complemented by a task description of supporting care outside the hospital. The double aim of supplying adequate palliative measures to the patient and at the same time supporting the ordinary staff in the acquisition of increased palliative knowledge should help improve the treatment of all incurably ill people.

By referring all patients to specialized palliative care units, we lose this gradual transfer of knowledge and rather end up with less and less experience of palliative care in ordinary hospital wards and nursing homes. With more than 1% of the population dying each year and of those 80% dying the "slow death" from an incurable disease, the number of patients with unmet palliative needs would be overwhelming. Every care institution and care organization has to realize that the incurable and dying patient is not a rare excep-

tion but a regular challenge that requires specific routines and skills to ensure efficient optimal care including both symptom control and family support.

Wide distances and scarcity of people

Specific problems in sparsely populated areas are wide distances and the scarcity of both patients and professionals. The Swedish experience is that it is possible for a specialized palliative home care team to occasionally (median = doctor visits twice during their time of support) do home visits within a radius of 250 kilometres. These visits are mainly planned visits decided on one or two days before. They are always done with the local district nurse and they take between one and two hours in the home of the patient. During this time, the physician goes through what has happened, how it is now, what the patient and the family (separately) thinks/fears about the near future, physical examination of the patient, prescription/adjustment of drugs, information of the expected symptomatology, available treatment opportunities, when and if hospital care is required, and when it is not medically indicated.

Whether the travelling time is 30 minutes or 2.5 hours one way does not affect the patient and their next of kin. Their main interest is that someone skilled in palliative care arrives at their home to provide the needed palliative care. In this phase of the disease trajectory (with very limited time left to live and when hospital care increasingly

often is not medically indicated), to transport healthy professionals to the home of the incurably ill is more rational than to transport weak incurably ill patients far distances to hospital. Due to the use of modern technology such as mobile phones and wireless access to medical records, the travelling time can be used for phone calls to medical colleagues or non-present family members, for writing drug prescriptions, or for conducting informative discussions with other palliative patients supported by the team.

A specialized team in sparsely populated areas has to rely on local care providers such as GPs, district nurses, and home care teams. In the county of Jämtland since 1992, the out-of-office coverage by district nurses has been facilitated by the fact that they are employed by the local municipalities as are the nurses at the local nursing homes. This implies that they are on call for both home care patients and the local nursing homes in their district, which makes this kind of organization reasonably cost effective. Many other counties with vast areas and sparse populations in the middle and northern parts of Sweden have been up to this year a divided organization for these nurses: The district nurses have been employed by the county council and the nursing home nurses by the local municipality. This arrangement results in unreasonably high costs for double nurse coverage during out-of-hour coverage in these areas. This divided responsibility often means no nurses are available for home care patients during out-of-office hours.

General versus specialized palliative care

The interface between general and specialized palliative care is always a focus for debate. No doubt that every clinically involved physician, surgeon, and GP will meet frequent incurable and dying patients in their every day clinical practise and thus have to be in command of general palliative knowledge that enables them to handle and treat an “uncomplicated” end-of-life patient in an acceptable way. At the other extreme, there is no doubt that there among all these “routine” cases will appear patients where their needs exceed the competence of the local team and the assistance of a palliative consultant or referral to specialized palliative care is appropriate. If this border between these competences is not fixed but relative to the competence of the local team and the complexity of the patients’ problems, it follows that the definition of specialized palliative care is also relative and flexible. Everyone with experience in palliative care also knows that a “complex” patient can transform to a non-complex patient and vice versa depending on the disease development and whether appropriate measures are offered.

The challenge

The challenge for Swedish palliative medicine is to reach out beyond its own specialized units and thereby make its unique competence available to patients and colleagues irrespective of palliative needs. By doing so, palliative medicine itself will learn by facing demanding clinical situations with

palliative challenges within geriatrics, cardiology, neurology, chest medicine, nephrology, and other specialities. This invaluable knowledge will ensure that the patients who are in the most need of help receive care from specialized palliative units. In addition, this will enable mutually respectful collaboration with colleagues from all clinical specialities when offering palliative consultative support.

Time has now come in Sweden for a common national infrastructure that makes optimal palliative care available all over the country according to need and according to a predetermined pattern. Several factors will promote further positive developments within palliative care in Sweden: the establishment of national standards of palliative care; the recognition that palliative medicine is a speciality form of medicine (this will begin in 2014); and the use of a Swedish Registry of Palliative Care (6). As the Registry of Palliative Care now includes substantial national coverage (55% of all deaths in the country), on-line follow up of the palliative care content during the last week of life is now possible. The experiences in the counties of northern Sweden show that even sparsely populated areas are possible to include in a plan for national coverage as long as the infrastructure is tailored according to local conditions.

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