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Experiences with Palliative Care in Rural Regions in Germany

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Abstract

A description of the historical development of outpatient palliative care in Germany is followed by a presentation of the specifics of rural care provision. Drawing on this situation, the authors describe an established network model, which can assure the type of care that patients and their relatives in rural areas want and which allows dying in dignity at home to be an option for the majority of affected patients, in line with their wishes.

Keywords: Palliative care; Rural regions; Networks; Health care education

Development of Heterogeneous Care Structures

Influenced by developments in the United Kingdom, the history of palliative care in Germany began with isolated initiatives during the eighties, which progressed to become widespread reality from the beginning of the nineties. Initial pilot projects were run and developed, in particular by office-based oncologists who provided complex care to their incurably ill patients, over and beyond just tumor therapy [1,2]. One problem was that numerous, and sometimes very heterogeneous, initiatives were developed which were strongly influenced by the respective region, health care provider and the intentions of the respective patient carer involved. However, these services are usually very laborious and demanding and have not been funded by health care insurance providers so far. Nevertheless, it has been easier to establish outpatient palliative care in large towns, with their high population density and the associated short distances, than in rural areas. Furthermore, the infrastructure in towns is usually more resilient than in rural areas, for example with the availability of specialist hospital departments, specialist doctors, hospices, care providers, etc. From a survey of outpatient nursing services in the Free State of Saxony published in 2012 it became clearly evident that in economically strained times only the service providers operating within palliative care networks were able to cover their costs [3].

Even after the 106th German Medical Assembly had identified serious shortcomings in palliative care provision in 2003 and the German Federal Parliament had commissioned an experts' report on the situation of palliative care in Germany [4], it was not until 2007 that the entitlement to benefit from specialist outpatient palliative care for patients with statutory health insurance was defined by law. Since then the health insurance funds have been responsible for negotiating regional health care contracts with appropriately qualified service providers, giving particular consideration to those providers already active in a particular region when assigning mandates to provide care.

Specifics of Rural Palliative Care

Even after almost ten years of specialist outpatient palliative care in Germany, a few regions still remain not provided for. Care provision of urban regions was ensured relatively quickly, particularly since large hospitals and university hospitals are obliged to have outpatient palliative care available for training purposes. The creation of efficient care systems in provincial and rural areas proved to be considerably more problematic. Even in the Free State of Saxony, which is more or less an industrial region, 66% of the inhabitants live in rural districts [5]. While, on the one hand, inpatient facilities must be kept available in the regional hospitals for the care of these patients, structures which take the special circumstances of rural areas into consideration must also be developed for outpatient care. Unlike urban environments, these rural areas are characterized as follows:

- Lower population density and thus lower patient density
- Significantly longer routes for house calls
- Ageing primary care physicians, significantly lower physician density
- Small, usually non-specialist hospitals
- Conservatively oriented doctors and population
- Fewer and non-specialist pharmacies

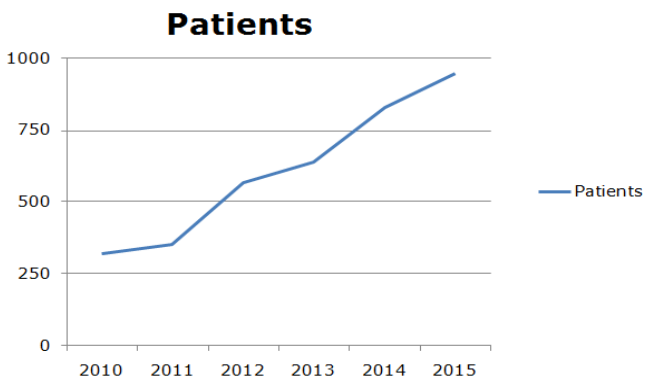

Figure 1: Development of patient numbers per year of the service provider Home Care Sachsen, Dresden.

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Table 1: Levels and care functions within the network.

Level	Involved parties	Assignment
1	Family carers and professional carers, palliative care	Emotionally responsive care-giving, support and care, attendance, therapeutic communication
2	Specialist carers	Supervision, education, therapy monitoring, coordination with the doctor
3	Primary care physicians (GP); palliative care medicine	Primary care physician and specialist medical attention, treatment adaptation
4	Pharmacists, dietary counselling, social workers, chaplains, psychologists, speech therapists, physiotherapy, ergotherapy, hospice team	Intervention, care, information, specialist support

- Significantly less well developed public transport system

- Less representation by public authorities and health insurance funds

Nevertheless, the rural at-home mortality rate for oncologic patients - also unlike urban environments - is significantly higher at 48 to 50% than in towns, most likely as a result of intact family and neighborly ties and thus also preserved care structures [6]. By providing specialist outpatient palliative care, the at-home mortality rate can be increased even further to approx. 80%. This is also in line with the wish of the majority of patients [7].

Development of Care Structures

In the structurally problematic rural care provision area, this goal can be achieved primarily by establishing health-care networks in collaboration with existing structures. Apart from family carers, community nursing services and the regional palliative care team are the ones closest to the patient. This level is followed by specialist nursing care at a second level, with their staff creating a bridge to the medical care located at a third level; here there are the primary-care physicians and doctors specializing in palliative medicine. A fourth, more distant level links up the required service providers when necessary, such as pharmacists, physiotherapists, hospice team, chaplains, psychologists, ecotrophologists, etc. (Table 1).

The palliative care provider has an important function here with its qualified staff, training, instructing and supervising the family carers on the one hand and also the local professional carers, on the other.

In the majority of cases the transfer of patient care takes place via the specialist, the primary care physician or the hospital. First of all a detailed history of the patient's current condition is taken. In this regard, the will of the patient and consultation with all partners involved in the patient's care are of utmost importance. The specially trained staff endeavors to support the relatives and patients in their new situation in the best possible way and to achieve the highest degree of quality of life. Furthermore, regular follow-up reviews and a periodic evaluation of the common objectives defined at the start of every therapy are conducted. The palliative carer acts as an intermediary between doctor and patient, patient and carers, patient and outpatient palliative care team. All relevant data and changes are thus promptly passed on to the appropriate contact person thanks to the most up-to-date technology. Short-time communication between all integrated carers is very necessary; also a further education and qualification to achieve and keep an equal level of thinking and acting [8].

There is without doubt a need for supportive care and, where appropriate care structures are available, the provision of specialist outpatient palliative care is gratefully welcomed. Figure 1 shows the development of patient numbers per year of the outpatient palliative care provider Home Care Sachsen, Dresden, the largest service provider in the Free State of Saxony, from its accreditation in 2010 to 2015. Following the implementation of the described network model for medical care in rural areas, Home Care Sachsen e.V. has been able to achieve an at-home mortality rate of 77% for the 3815 palliative care patients they have so far cared for. This is consistent with the will of the majority of patients, while, on the other hand, enabling considerable costs for inpatient and emergency service capacities to be saved in this way [9].

Prospects

The described network structure in rural outpatient palliative care provision has been further optimized by the establishment of a mobile digital communication system which, on the one hand, allows carers and doctors to access a continually updated database simultaneously, while, on the other hand, it also enables them to maintain contact with patients and family carers utilizing the potentials of telemedicine.

Conclusion

Outpatient palliative care in rural regions is a challenge for all carers. In contrast to urban settings there are many factors that influence providing palliative care. The authors report about their experiences with a multiprofessional and interdisciplinary four-level-network to provide palliative care. Using the palliative care network including medical staff and health care providers most of the patients can die at home as they wanted. This model is a possible way for realizing outpatient palliative care in rural regions. Most important implication for practice is the need to build up networks through integrating local carers. Community nurses and General Practitioners must be qualified following a special structured schedule. Short-term changing informations about the patients performance status and needs between all involved carers is necessary.

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