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Danish Center for Evaluation and Health Technology Assessment

HOSPICE WITHOUT WALLS
- A HEALTH TECHNOLOGY ASSESSMENT OF A PALLIATIVE NETWORK
SUMMARY

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Summary

Within an HTA-framework, the palliative effort within a palliative network – 'Hospice without Walls' in the municipalities of Odder and Skanderborg – has been evaluated systematically.

In the choice of technology as well as treatment and nursing care in the terminal phase, a dilemma has been incorporated out of consideration for the individual and the society. On one hand, the main purpose of the offers that are given to a dying person in the time that the patient has left must be to contribute to a decent ending of life. Undoubtedly, this is one of the central elements in a palliative effort. However, on the other hand, a palliative effort will from a societal perspective – other things being equal – also be assessed and prioritised by the decision-makers from an economic point of view. The main reason for this is that the decision-makers need to keep their budget, as well as they have to maximise the benefits within a given resource limit. In relation hereto, the Danish Parliament did decide to establish a hospice pool on 20 million DKK in support of the establishment of hospices in the Danish counties.

On the basis of the above-mentioned, this evaluation of 'Hospice without Walls', which is based on a health technology assessment, can be said to form a many-sided and wide foundation for an evaluation that both includes conditions and benefits to the individual and the society. Consequently, this evaluation may constitute a wide and many-sided foundation for a decision-making process.

The purpose of the health technology assessment has been to investigate the consequences of a network-based organisation like 'Hospice without Walls' compared to a more sector divided effort. The overall planning question of the project is:

- What are the consequences to the pain treatment, the palliative care, the patient, the organisation, the personnel and the economy of establishing a 'Hospice without Walls' in the sense of a palliative network within an area like the municipalities of Skanderborg and Odder?

'Hospice without Walls' (2001-2002) has been compared with a corresponding "before period" (1999-2000), where the palliative effort was more sector divided as well as the palliation was carried out on a more basic level compared to a highly specialised level in 'Hospice without Walls'. In connection with the project, a number of investigations have been carried out by means of different methods depending on what was suitable and possible. Consequently, data collection methods such as systematic journal reviews, case sequence descriptions, literature reviews, surveys, individual interviews as well as focus group interviews have been applied. In relation hereto, it should be emphasised that some of these investigations due to practical reasons must be characterised as random samples, and for one investigation there was no standard of comparison with the "before period" (the survey among the relatives). This of course results in limitations as to the validity of the conclusions.

The specific results from each of the investigations are not mentioned in the summary. Instead, the main results and conclusions are summarised within each of the four main elements of the HTA-project. The main results and the conclusions of the report is in the end put into perspective for the future use in connection with initiatives that are similar to 'Hospice without Walls'.

Technology

As concerns the technology – with focus on pain management and palliative treatment and care – the HTA-project has indicated that the consequence of 'Hospice without Walls' to the pain management of the terminal patient is that the treatment has become more potent and, consequently, is expected to provide a faster pain palliation. This expectation is based on the systematic journal review as well as on an acknowledged pain classification from WHO (2003). Furthermore, the focus on palliative symptoms and problems has increased – both in hospitals as well as among the care and nursing staff in the nursing care at home, as more symptoms and problems seems to have been identified in relation to 'Hospice without Walls' as well as more palliative initiatives have been established for relief.

Summary in: Poulsen PB, Kolbye A, Rajani N, Hornamnn A. Hospice without Walls – a Health Technology Assessment of a palliative network.
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In Danish. Full length pdf at www.dacehta.dk

Some results indicate that the possibility of "open" hospitalisation according to requirements is utilised more frequently in 'Hospice without Walls' compared with before. However, it has not been possible to confirm this assumption based on the analysed bed-duration data. The use of respite care in the two nursing homes in the municipalities of Odder and Skanderborg has also increased.

However, based on the HTA-project, it has not been possible to document that the bed-duration in the hospitals has been reduced as a consequence of 'Hospice without Walls'. It was, however, to a certain degree expected that this would be the case, which is why it also represented an underlying motivation for establishing 'Hospice without Walls'. If anything, the total days of inpatient stay in the hospital of the individual patient at the terminal stage has been increased compared with before as well as a greater part of this inpatient stay consists of more short hospital stays. One of the reasons for a longer inpatient stay may be that the pain management is more optimal today, as it is adjusted in relation to palliative symptoms of the individual patient, which is expected to contribute to a longer life of the patients and thereby more hospital visits and stays. However, it has not been possible to confirm this assumption in the HTA-project.

Finally, it was expected that 'Hospice without Walls' had made it possible for more patients to die in their own homes. This, however, has not been documented on the basis of a comparison with data from the before period from the journal review, as the number of patients, who died in their own home, remained unchanged after the establishment of 'Hospice without Walls'. This, however, does not mean that the terminal patients have not been able to stay in their own homes as long as possible.

The organisation

The greatest changes as a consequence of the establishment of 'Hospice without Walls' seem to be found within the organisation, including the structure and the culture. 'Hospice without Walls' has been well received by the different partners and personnel groups within the hospital and the primary sector, as the acceptance of 'Hospice without Walls' in general has been very positive. One of the primary reasons for this is that 'Hospice without Walls' to a great extent is based on the existing structures and framework. However, in connection with the project, differences between cultures and practices within the cross-sectorial cooperation – especially between the hospitals and the GPs – have occurred.

The starting point of 'Hospice without Walls' has been that the palliative team consists of the pain clinic represented by a pain nurse and an anaesthesiologist in cooperation with the contact nurse from the home care and a GP. In relation to the structure – and especially in relation to the management and the responsibility of the patient – this has to a certain degree not been realised in practice. According to some GPs – primarily in Odder – the pain management team in the hospital and its role as an outgoing team is too dominant. Consequently, the GPs sometimes feel that they are no longer a part of the patient treatment. The pain clinic has tried to involve all parties, including the GPs. However, in the beginning of the project, the interest from the GPs was not very big. It is however, very important that the GPs know what it means to cooperate within palliative treatment on a highly specialised level instead of on a basic level in order for them to be able to work as a coordinator within patient treatment.

However, the risk of not continuing the work with 'Hospice without Walls' is that the management and the responsibility for the patient will not be deeply rooted anywhere. This may complicate the maintenance of coherent patient sequences between sectors (shared care). Furthermore, the lack of a follow-up on the problem may have the negative effect that the GPs in some cases will be reluctant to cooperate. In the end, this may have consequences to the patient, as he or she may feel like being thrown backwards and forwards between two sectors.

This may not necessarily be a big problem in 'Hospice without Walls'. It is possible to argue that the development and the anchoring of a cross-sectorial cooperation take more than three years. The problems do not only apply to 'Hospice without Walls'. Such problems are to be expected in all shared care connections involving cross-sectorial cooperation – especially in relation to hospital teams with an outgoing function. The problem in such co-operations will always be the division of labour between two sectors. Others, who may consider implementing similar palliative teams unified in one network across sectors must pay attention the problems that may arise and prepare themselves the best possible way.

However, besides the above-mentioned problems, the inter-sectorial network cooperation in 'Hospice without Walls' generally has worked well. It may, however, be argued that more different professionals such as

physiotherapists, psychologists and priests should have been attached to 'Hospice without Walls', as the model in more than one respect not has been sufficient.

The patient

Based on a retrospective survey after the patient's death, the relatives have been asked questions as a proxy for the patient regarding practical and factual conditions in the terminal sequence as well as estimations regarding the terminal sequence. This both due to ethic as well as practical reasons. The method, however, is not unknown when it comes to palliative initiatives, as it has been applied in several other studies. Furthermore, research has shown that generally the relatives agree with the patients, when it comes to factual questions.

As concerns the patients' reactions to 'Hospice without Walls', they have almost exclusively been positive. In this way, 92% of the 102 relatives that have been asked think that 'Hospice without Walls' has been a very good or a good help to the terminal patient and their relatives. Only very few relatives have had a negative attitude towards 'Hospice without Walls'. All in all, the support to the terminal patient and the relatives has been sufficient in most cases. However, it is still possible to improve the initiative in different ways, for instance, more support should be given in relation to preparing the relatives for the loss and the grief that will arise, when the terminal patient dies. Many of the relatives express that 'Hospice without Walls' has made it possible for their dying relative to stay in their private home during the last time they have left. The only criticism from the relatives is the GPs lack of involvement.

The voluntary visitor is another offer within 'Hospice without Walls'. The sequences (9%) that the voluntary visitors have been involved in have been positive. In more incidences, the voluntary visitor has been involved in the sequence very late in the patient's terminal sequence, why some sequences have been very short. As an established offer with reference to the pain clinic, the work of the voluntary cooperation – both with the patient and its relatives as well as with the professional parties – has been good.

The economy

The expectation in relation to the economic consequences of the establishment of 'Hospice without Walls' was that it would lead to a saving in the hospital as a consequence of less and shorter inpatient stay in the hospital. This HTA-project has, however, based on a marginal analysis, demonstrated that this does not seem to be the case.

'Hospice without Walls' does not result in any savings; on the contrary it involves an increase – yet limited – in the costs. 'Hospice without Walls' is an alternative that may be characterised as being both better and more expensive. Per patient this means an extra cost of DKK 15,000 to DKK 64,000 in 'Hospice without Walls' – depending on the specific assumptions and the municipality in question. Compared to this year's annual expenses to a hospice bed, which according to Danish County Councils Association costs around DKK 1 million per year, or compared to an ordinary hospital bed, which is likely to be more expensive, it is assumed that 'Hospice without Walls' is a cheaper alternative, if the costs are considered separately. Furthermore, the extra resources for 'Hospice without Walls' must be counterbalanced with the advantages to the patient and his or her relatives.

Furthermore, the HTA-project has put down the myths saying that 'Hospice without Walls' by means of the increased activity in the municipalities and in the respite care has meant that Aarhus County has saved money at the expense of the municipalities of Odder and Skanderborg. From an economic point of view, an implementation of 'Hospice without Walls' means that all budgets will be increased to some degree, which is why no one can be said to be the actual winners in this respect. Actually, Aarhus County is the one that carries the biggest expenditure in most calculation scenarios.

Putting into perspective

In general, this HTA-project gives the impression of a palliative network with several obvious advantages to the patient, the relatives and the personnel. However, the HTA-project has also illustrated that improvements

are required within certain areas. Counties and hospitals, which do not have palliative teams or only teams with limited outgoing functions as well as cooperation with the primary sector, may benefit from some of the experiences learnt from 'Hospice without Walls'.

In relation to the debate concerning the establishment and the extension of hospices in Denmark it should be emphasised that 'Hospice without Walls' is *not* an alternative to an actual hospice. The palliative teams, which 'Hospice without Walls' represents, on the contrary applies to a larger group of terminal patients, who wish to die in their own homes and, consequently, employ the different offers that exist instead of spending the last time of their lives in a hospital. Many of theses patients will not be relevant for a hospice, however, they still deserve some attention.

The experiences and elements from 'Hospice without Walls' may be used in other counties with the primary focus on palliation on a highly specialised level. Furthermore, focus should be on coherent patient sequences for the terminal patient and relatives as well as a fulfilment of the wishes that the patient may have in the last period of his or her life.