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# Outpatient palliative care effectiveness: both patients and caregivers can gain

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**Evaluation of:** Groh G, Vyhnaek B, Feddersen B, Fuhrer M, Borasio GD. Effectiveness of a specialized outpatient palliative care service as experienced by patients and caregivers. *J. Palliat. Med.* 16(8), 848–856 (2013).

Outpatient palliative care services are increasing in their effectiveness worldwide, because they can better focus on both patients' and caregivers' needs at all stages of the disease requiring this type of interventions. This was demonstrated before by various studies that, however, were performed mostly on patients with malignancies and that yielded encouraging results about the severity of the symptoms and about the burden of care in the caregivers. In this analysis performed on a mixture of patients with malignant and nonmalignant diseases, Groh *et al.* demonstrate that the outpatient team intervention was able to reduce the severity of symptoms such as pain or digestive symptoms and were able to minimize the burden of care of the primary caregivers.

**KEYWORDS:** caregiver • effectiveness • fatigue • malignancies • pain;outpatient • quality of life • palliative care

Palliative care services can be delivered in various settings such as hospice, hospital or at home and have among the main aims the increase in quality of life of patients and of caregivers and in minimizing the distress provoked to both by a chronic debilitating non-malignant disease or by a malignant condition. Sometimes the events requiring palliative care interventions cannot be treated at home, but in many cases, many problems can be solved by domiciliary interventions that allow the patient to benefit from receiving them in a familiar environment. If it is the case of the last days of life, then such interventions can increase the well-being of the patient and of the caregivers and can allow the former to die peacefully at their preferred location [1].

Various studies have demonstrated this, most frequently in patients with malignancies, and the data analyzed by Groh *et al.* tested the same hypothesis on a mixture of patients with non-malignant and malignant conditions and on their primary caregivers [2].

## Methods & results

This was a prospective study performed by a specialized outpatient palliative care (SOPC)

interdisciplinary team, which analyzed the effectiveness of the delivered healthcare services on patients and on their caregivers. Included were patients requiring and receiving palliative care as outpatients and their primary (not paid) caregivers who consented to participate to the study [2].

Patients who were willing and able to fill in questionnaires, were given two satisfaction with care tools that were under development, as well as other (already validated) questionnaires or tools such as the McGill Quality of Life Questionnaire, the Minimal Documentations System for Palliative Medicine (MIDOS) and the Palliative Outcome Scale, which had to be completed before and after receiving the SOPC team.

Caregivers were asked to fill in the caregiver versions of the questionnaire under development, the Quality of Life in Life-Threatening Illness-Caregiver version (QOLTI-F), the Hospital Anxiety and Depression scale (HADS) and the Home Care scale before and after the interaction with the SOPC team.

Of the 100 patients visited over the study period, 60 patients were considered eligible, but 23 (38%) were ill or refused to fill in the questionnaires and five more died before the second assessment took place. Most of the patients

33 (55%) were males and the median age was 67.5 years, most of the patients had a malignancy ( $n = 52$ ; 87%) and most of them had a cancer in the gastrointestinal tract ( $n = 21$ ; 35%). The median duration between the two assessments was 2.5 weeks (few days to 7 weeks range).

A total of 53 caregivers were included in the study, 41 (77%) being females, the median age being 58 (29–91 years range), most of them being spouse/partners (64%) or parents (20%).

The effectiveness of the care provided by the SOPC was assessed with satisfaction with care, care burden relief (reduction) as perceived by the patients, respectively, by the caregivers and by a more complex outcome measure defined as patients' and caregivers' adjustment after the interventions delivered by the SOPC which included for the patients quality of life, symptoms' control, respectively, for the caregivers quality of life, related stress and burden.

SOPC interventions were able to increase significantly the satisfaction with care for both patients and caregivers as demonstrated by the tested questionnaires' scores. The burden of care was significantly diminished by the same interventions as perceived by both patients and caregivers themselves and expressed by the scores of numerical scales. The main strengths were represented by the psychological support, by the interventions related to the activities of daily living, by the information on the disease status and trajectory delivered to both patients and carers. The delivered interventions, however, were not able to improve the quality of the spiritual care and that of communication with general practitioners and other healthcare providers, for both tested parties.

SOPC team interventions were also able to improve both patients' and carers' adjustments: in patients, this was demonstrated by the significant improvement in the MCQ questionnaire score (interquartile range [IQR]: 4.5 before and 6 afterwards;  $p < 0.001$ ), in the Palliative Outcome Scale, the total score (IQR: 25 before, 14.5 afterwards;  $p < 0.001$ ) and by the significant improvement in pain, nausea, vomiting, anorexia, depression and well-being scores (as assessed by MIDOS). In caregivers, this was demonstrated by the significant improvements in satisfaction quantified with a numerical scale and by the improvement in the QOLTI-F (IQR: 6.1 before, 7.3 afterwards;  $p < 0.001$ ), HADS scores (IQR: 22 before and 16 afterwards;  $p < 0.001$ ) and HPS scores (IQR: 13 before and 9 afterwards;  $p < 0.001$ ).

## Discussion

This analysis demonstrates that the intervention of an outpatient palliative care team is able to reduce both the disease and the care-related burdens. In terms of disease burden, the

interventions provided by such a team could reduce or make to disappear major symptoms such as pain or nausea, although no significant effects were found on others such as fatigue or dyspnea. Such results can be partially explained by the fact that among the analyzed patients, a significant proportion had digestive malignancies and that at least in the case of dyspnea, based on the results discussed by the authors, the severity of this symptom did not seem to be very significant.

## Expert commentary & five year view

The fact that the major symptoms such as fatigue, depression or dyspnea could not be significantly improved by an unique intervention of an outpatient palliative care team that however was able to improve the pain or nausea, for example, raise the question of the need to repeat such interventions and to tailor the next episodes of these activities to address what the previous interventions were not able to correct. For the dyspnea in particular, for example, other research teams are exploring it in some ongoing studies: the soundness of such an approach is currently assessed with a home-outpatient clinic combined approach in an ongoing study [3]. In the case of fatigue, in another study already performed on oncology patients, the first set of interventions did not improve the severity of fatigue, whereas after the second set of interventions, this decreased significantly [4].

Psychoemotional symptoms such as depression and anxiety remain the most difficult to address in one intervention and, therefore, a periodic nursing intervention aimed at detecting persons at risk and followed by a sustained multidisciplinary approach seem to be the way forward for these burdensome symptoms.

Overall, the results of this study encouraged the expansion of such teams that are extremely useful especially at the both extremes of palliative interventions: early palliation in patients requiring it and mainly aimed to improve the quality of life and to prevent hospitalizations, and end-of-life patients in whom the interventions are no longer able to improve the quality of life in such a sustained manner as the early palliation, but are mainly targeting the well-being and the comfort of the patients as well the reduction of the distress of the caregivers.

## Financial & competing interests disclosure

*The author has no relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties.*

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## Key issues

- Palliative care interventions are aimed at increasing the quality of life of patients with life-threatening or terminal illnesses and can be delivered at home, at hospice and in hospital.
- Palliative care outpatient's services have the advantage of being useful at any phase of the disease requiring specific interventions, that is, during early phase as well as during last days of life.
- End-of-life outpatient palliative care services can increase the comfort of the patients and of their caregivers and can allow the formers to die peacefully in their preferred environment.
- Many studies demonstrated that such services are able to improve the quality of life in patients and caregivers.
- Palliative care outpatient's services are also able to reduce the symptom as well as the care burden in patients, respectively, in caregivers.
- The discussed paper demonstrates in a population of patients with both malignant and nonmalignant patients that this type of intervention is able to increase the quality of life and to reduce the severity of symptoms such as pain or nausea.
- In the same study, it was demonstrated that targeted interventions were able to reduce the emotional distress, the burden of care and to improve the quality of life in the caregivers.

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