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Informal caregiver strain, preference and satisfaction in hospital-at-home and usual hospital care for COPD exacerbations: Results of a randomised controlled trial

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ABSTRACT

Background: Informal caregivers play an important role in hospital-at-home schemes. However they may increase their burden, especially chronic diseases, like COPD. In the absence of clear differences in effectiveness and cost-effectiveness between hospital-at-home and usual hospital care, informal caregiver preferences play an important role. This study investigated informal caregiver strain, satisfaction and preferences for place of treatment with a community-based hospital-at-homes scheme for COPD exacerbations.
Method: The study was part of a larger randomised controlled trial. By randomisation, patients were allocated to usual hospital care or hospital-at-home, which included discharge at day 4 of admission, followed by home treatment with homes visits by community nurses until day 7 of treatment. Patients allocated to usual hospital care received care as usual in the hospital and were discharged at day 7. Patients were asked if they had an informal caregiver and who this was. Patients and their caregivers were followed for 90 days. Informal caregiver strain was assessed with the caregiver strain index. Satisfaction and preference were assessed using questionnaires. All measurements were performed at the end of the 7-day treatment and the end of the 90-days follow-up.
Findings: Of the 139 patients, 124 had an informal caregiver, of whom three-quarter was the patients' spouse. There was no significant difference in caregiver strain between hospital-at-home and usual hospital care at both time points (mean difference at $T+4$ days 0.47 95% CI −0.96 to 1.91, $p=0.514$; mean difference at $T+90$ days 0.36 95% CI −1.85 to 1.35, $p=0.634$). At the end of the 7-day treatment, 33% ($N=15$) of caregivers of patients allocated to hospital treatment and 71% ($N=37$) of caregivers of patients allocated to home treatment preferred home treatment, if they could choose. Caregivers were satisfied with the treatment the patient received within hospital-at-home.
Conclusion: There were no differences in caregiver strain between the community-based hospital-at-home scheme and usual hospital care. Most caregivers were satisfied with the treatment. In addition to other outcomes, our results support the wider implementation of hospital-at-home for COPD exacerbations.

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What is already known about the topic?

- Informal caregivers play an important role in hospital-at-home schemes, therefore these schemes should also be evaluated from their perspective.
- Informal caregiver strain and satisfaction in hospital-at-home schemes are not different from that in usual hospital care, but most schemes admit patients with various conditions and treatment.
- Effectiveness and cost-effectiveness of hospital-at-home and usual hospital care for COPD exacerbations are not different, therefore the choice between the two should be based on informal caregiver preferences, in addition to patient preference.

What this paper adds

- This paper is the first to evaluate hospital-at-home for COPD exacerbations solely from the perspective of informal caregivers.
- This study demonstrates that informal caregiver strain in hospital-at-home for COPD exacerbations is not different from that in usual hospital care.
- Informal caregivers' satisfaction with care provided to patients within hospital-at-home is high and the majority prefers hospital-at-home treatment for the patient if they could choose.

1. Introduction

Exacerbations of Chronic Obstructive Pulmonary Disease (COPD) are responsible for a high number of the annual hospital admissions and consequently high health care costs (Toy et al., 2010). Hospital-at-home for COPD exacerbations is an alternative for hospital treatment that aims to reduce the number of admissions and/or the duration of hospital stay. Forty-four percent of British hospitals run a hospital-at-home scheme for COPD exacerbations (Quantrill et al., 2007).

Several studies have shown that these schemes have no adverse effects on patient outcomes, and that patients are satisfied with hospital-at-home (Shepperd et al., 2008, 2009). Informal caregivers play an important role in hospital-at-home schemes, often providing additional care for needs unmet by professional facilities (Montalto, 2002). Although the shift of care from hospital to home might impact caregiver burden, limited results are available on informal caregivers' experiences in hospital-at-home schemes.

Previous studies on informal caregiver strain in hospital-at-home have found no differences between hospital-at-home care and hospital care (Gunnell et al., 2000; Shepperd et al., 1998). Furthermore, caregivers were satisfied with the care the patient received within hospital-at-home compared to hospital care (Caplan et al., 1999; Leff et al., 2006, 2008; Montalto, 1996; Ojoo et al., 2002; Skwarska et al., 2000; Wilson et al., 2002). However, the studies evaluating informal caregiver strain and satisfaction in hospital-at-home were generic schemes, rather than disease specific. Chronic conditions, like COPD, already have a considerable impact on informal caregivers in general (Baanders and Heijmans, 2007; Sexton and Munro, 1985). Patients suffering from COPD face physical limitations in their excercise tolerance due to symptoms of dyspnoea and fatigue (NICE, 2010), and a high prevelance of psychological distress (e.g. depression and anxiety) (Yohannes et al., 2010). Living with COPD patients means being faced with these symptoms, which consequently may affect informal caregivers. Indeed, increased (personal) caring tasks, loss of personal liberty, witnessing patients' breathlesness, changing roles and interaction between spouses is physically and emotionally distressing and may lead to reduced well-being of informal caregivers (Grant et al., 2012).

In the hospital-at-home evaluation by Shepperd et al. (1998), caregivers for patients with COPD had much worse scores than the other patient groups, which included patients with hip and knee replacement, patients with hysterectomy and elderly medical patients. Specific evaluations of effects on informal caregivers of COPD patients are needed to evaluate if hospital-at-home has an effect on them, and if so, which effects. In addition, only few results on caregiver preference for treatment place and satisfaction with care are available (Ojoo et al., 2002; Schofield et al., 2006).

The current study evaluates a hospital-at-home scheme for COPD exacerbations from the perspective of the informal caregivers. The study had three objectives: (1) to compare informal caregiver strain in hospital-at-home and usual hospital care, (2) to compare informal caregivers' satisfaction with hospital-at-home and hospital care, and (3) to compare preferences for treatment place from informal caregivers of patients cared for in the hospital and at home, and which factors are associated with this preference. The study was part of a randomised controlled trial that had as primary objective to assess effectiveness and cost-effectiveness of hospital-at-home (Utens et al., 2010). Previous results from this study have shown that patient outcomes were similar for hospital-at-home and usual hospital care (Utens et al., 2012) and that there was no large cost difference (Goosens et al., 2013). In addition, patients were very satisfied with hospital-at-home scheme and a majority would choose hospital-at-home, if there were a choice (Utens et al., 2013).

2. Methods

2.1. Design and study objects

During the first three days of the admission patients were asked if they had an informal caregiver, and if so, who the main informal caregiver was. Main informal caregiver is someone close to the patient who provides additional support. The support could be emotional, physical or practical. The trial took place between November 2007 and March 2011 in 6 teaching hospitals in the South-east of the Netherlands and 3 home care organisations. Patients admitted due to an exacerbation of their COPD were screened for eligibility to participate in the trial on the first day of admission. Patients had to be aged 40 or older, diagnosed with COPD (i.e. at least GOLD stage I and 10 smoking pack years), hospitalised with an exacerbation

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