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## Original research

# The effect of structured personal care on diabetes symptoms and self-rated health over 14 years after diabetes diagnosis

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## ABSTRACT

**Aims:** To explore the effect of structured personal care on diabetes symptoms and self-rated health over 14 years after diabetes diagnosis while patients are gradually diagnosed with other chronic conditions (multimorbidity).

**Methods:** Post hoc analysis of the Danish randomized controlled trial Diabetes Care in General Practice including 1381 patients newly diagnosed with type 2 diabetes. The effect of structured personal care compared with routine care on diabetes symptoms and self-rated health was analysed 6 and 14 years after diagnosis with a generalized multilevel Rasch model.

**Results:** Structured personal care reduced the overall likelihood of reporting diabetes symptoms at the end of the intervention (OR 0.79; 95% CI: 0.64–0.97), but this effect was not explained by glycaemic control or multimorbidity. There was no effect of the intervention on diabetes symptoms after 14 years or on self-rated health after 6 years or 14 years.

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**Conclusions:** Structured personal care had a beneficial effect on diabetes symptoms 6 years after diagnosis, but not on self-rated health at either follow up point. To optimally manage patients over time it is important to supplement clinical information by information provided by the patients.

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## 1. Introduction

Diabetes studies commonly report intermediate clinical outcomes like blood glucose level, blood pressure, albuminuria, and body weight besides long-term outcomes like myocardial infarction and mortality [1]. Patient-reported outcomes (PROs) like symptoms, function, and self-rated health (SRH) are less commonly reported [2]. The purpose of medicine, besides prolonging life, is to improve quality of life and to reduce disability and symptom burden, however, only the patients themselves can adequately evaluate these aspects [3]. Symptoms can be defined as a “subjective evidence of disease or physical disturbance” [4] or as “any expression of disturbed function or structure of the body and mind by a patient” [5]. This implies that symptoms are subjective phenomena observed and interpreted by the patient and they sometimes lead to health care contact [6]. Symptoms are not necessarily signs of disease, but the patient’s story is nevertheless the most important source of information for the doctor when trying to establish a diagnosis [6,7]. SRH is, on the other hand, often measured with a single question: “how is your health in general?” rated on a four- or five-graded scale [8–10], and SRH covers both the individual’s understanding of health but also contextual factors and patient’s history [8,11]. The question is a widely used marker in public health studies [12–14] and it is well-documented that low SRH is associated with future complications like cardiovascular disease [14] and mortality [11–13,15]. These associations are especially pronounced in patients with diabetes [11,16] in whom SRH often decreases with increasing glycated haemoglobin (HbA1c) [9,17] SRH may, however, be associated with diabetic complications even when taking glycaemic control into consideration [18].

Patients with newly diagnosed clinical type 2 diabetes often present with typical diabetes symptoms, many of which persist after diagnosis [9,19,20] and those who experienced high self-reported illness burden independent of diabetes severity have a smaller increase in SRH during the first year after diagnosis compared to those not feeling burdened [21].

For diabetes patients with multimorbidity (i.e. additional chronic conditions), emotional distress [24], poor SRH, morbidity and mortality increase with the number of these additional diseases [25,26]. Diabetes is the condition included most often in definitions of multimorbidity [27], and multimorbid patients with diabetes report lower quality of life than patients with other combinations of multimorbidity [28]. Multimorbidity is associated with high illness burden [29] and when treating these patients self-care is essential [30].

For patients with multimorbidity patient-reported disease development appears to be at least as important as clinical risk factors [22]. Therefore, in order to understand how symp-

toms, treatments, and health care affect patients’ functional level and lived life, it is necessary to incorporate patients’ perspectives more systematically in health care [3,23].

In multimorbidity, the treatment of type 2 diabetes in particular requires lifestyle change and self-care and structured personal care involves patients in deciding the level of ambition for their own treatment [31]. Since treatment of patients’ diabetes is required for decades during which multimorbidity develops gradually, it is particularly important that indicators of treatment quality reported by the patients themselves should be added to the information we already have on complications and risk factors, also as time passes. Symptoms and SRH could be viewed as two separate, but interrelated aspects of patient-reported treatment quality.

Therefore, the aim of the present study was to explore the effect of structured personal care on diabetes symptoms and SRH during the first 14 years after diabetes diagnosis when patients are gradually diagnosed with multimorbidity.

## 2. Methods

### 2.1. Population

Data are from the Diabetes Care in General Practice (DCGP) study, a Danish cluster-randomized controlled trial of structured personal diabetes care with the participation of 474 general practitioners (GPs). During 1989–1992 1381 patients with newly diagnosed diabetes and aged  $\geq 40$  years were included in the trial (Fig. 1). Of these, 1369 (99.1%) were of Western European descent. Based on onset of insulin treatment, approximately 97.5% of the patients were considered to have type 2 diabetes [32].

### 2.2. Intervention

In the intervention group the GP and the patient were asked to agree on the best possible goal for controlling important risk factors with emphasis on glycaemic control with either (a) normalization of metabolism; which was considered relevant in young and middle-aged patients and in older well-motivated patients; (b) acceptable metabolic regulation, intended primarily for patients who were difficult to treat and/or difficult to motivate for treatment and for some older patients; or (c) freedom from symptoms. The latter treatment goal was only intended to be used when the course of treatment had demonstrated that goals beyond freedom from hyperglycaemic symptoms were unattainable [32]. Patients were invited by their GP to attend follow-up examinations quarterly and annual screening for diabetes complications. On all occasions treatment goals and achievements were nego-

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