Personalized care for community-dwelling older persons in general practice: moving towards greater involvement of patients

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General introduction

The world population represented by older persons is increasing rapidly, and many populations worldwide are ageing rapidly. This is partly due to a reduction in childhood mortality and, in high-income countries, to increasing life-expectancy in older age. Lower fertility rates also contribute to this demographic shift. By the middle of this century the proportion of the overall population represented by persons aged 60 years or older is expected to exceed 20% (12.3% in 2015). In many countries this proportion is likely to exceed 30% (1).

Older people are more likely to experience multimorbidity (i.e. multiple chronic conditions concurrently) and complex health problems. Complex health problems are a combination of limitations in different health domains (i.e. somatic, functional, psychological and/or social domain) that often interact with each other. Complex health problems also result in greater use of healthcare. In The Netherlands, the Dutch College of General Practitioners acknowledged that the healthcare demands of older persons will rise rapidly as the population ages while healthy life expectancy increases less fast (2). Anticipation of the increase in healthcare demands by older people has fostered an emerging field of research within, but not restricted to, medical sciences all around the world (3-5). In general, this research aims to find ways to improve healthcare for older people. For example, some studies have focused on quality of life amongst older persons (6, 7), while others have sought evidence for (cost-)effectiveness of a new approach to delivering healthcare (8).

The Netherlands was no exception, in 2008 The National Care for the Elderly Programme (NPO) initiated an extensive research program in an attempt to improve healthcare for older persons in (2008-2016). The organization of healthcare in The Netherlands differs from most other countries, due to the prominent role of primary care. Furthermore, in recent decades older persons have been encouraged to live at home longer. These two factors make it important to develop new, structured care for the growing group of community-dwelling older persons in primary care. The concept of structured, personalized care gave a new impulse to care development, with a focus on functional aspects of health for older persons in general and for community-dwelling older persons in particular (9). The focus of the around 200 projects that arose from the NPO was to help older persons to live their life as independently as possible, and to confer as much added value as possible, even as dependency increases.

However, some (inter)national studies aiming at improving medical care for older persons have produced inconclusive results. For example, large trials of promising interventions based on pro-active medical care for vulnerable older persons (selected with screening methods or case-finding) have reported little effect on negative health outcomes (e.g. a decline in functional status and independence, use of healthcare and mortality) in older persons (8, 10-21). Interestingly, older persons reported increased satisfaction regarding the care they experienced, despite the limited effects of the interventions on health outcomes

(21, 22). Professionals also often appreciated, and acknowledged, that they had gained better understanding of their older patients and their concerns (23). Implementation of these interventions in general practice was difficult because many of the interventions were time-consuming (16, 17). It was also noted in a meta-analysis that interventions tested in trials before 1993 were more often effective. This could perhaps suggests that usual care has improved over the last three decades, since many trials compared interventions to usual care (24). The results of these studies gave rise to new questions. For example a recent large trial to improve the care for people with multimorbidity in UK primary care suggested that the current methodology to measure quality of life is not sensitive enough to detect changes relevant to the patients (21). In the 'vision primary care for older persons' (2017) of the Dutch College for General Practice which outlines the future of personalized, integrated healthcare for older persons, questions on selection of groups at risk and use of different outcome measurements during evaluation are referred to as well (25). Therefore, we set out to study a different approach towards: 1) the selection of older persons who might benefit from an intervention, 2) the targeting of specific individual problems rather than offering a multidimensional intervention, and 3) the evaluation of individually selected problems and goals.

The ISCOPE study was one of the large trials performed within the NPO (17). This study used a screening questionnaire to identify older persons with complex health problems (17) and addressed the hypothesis that combined health problems are more difficult to manage than expected by the sum of those problems, especially when problems arise in different health domains (26). For older persons with complex health problems, a disease-specific approach is not sufficient. In ISCOPE, individual patient problems and goals were summarized in a care-action-plan, including the formulation of actions to reach these goals (27). In this thesis, data from this trial and new data from an ISCOPE follow-up study are further explored.

AIM AND OUTLINE OF THESIS

In line with recent trends towards value-based healthcare (optimizing value at the lowest cost), it is important that value is clearly defined in terms of what matters to the patient (28). This approach fits with the main focus of personalized healthcare: specific individual health problems. Clinicians strive towards further embedding of personalized healthcare in order to improve health outcomes and patient satisfaction. The overall aim of this thesis is to gain additional knowledge on wishes of older persons on this topic, and on possibilities for professionals to implement this personalized healthcare. Outcomes of the studies will be combined with current knowledge and guidelines to formulate evidence-based recommendations for personalized care for older persons in general practice. It is important to

understand how hindering health complaints affect the functional status of older persons. The level of urgency in tackling these problems depends on the impact of the health complaints on day-to-day life. This is described in part 1 of this thesis. In part 2, we examine possible improvements in the personalized care provided by GPs.

PART 1. IMPACT OF HEALTH COMPLAINTS

It is important to understand which problems older persons actually experience in daily life, how these hinder their daily life, and what older people require in order to remain independent and live life on their own terms. In the first part of this thesis two studies describe the occurrence and impact of hindering health complaints. In chapter 2, the presence and relevance of hindering health complaints in community-dwelling older persons is explored. Self-reported, hindering health complaints and the association with functional decline, quality of life, cognitive status, depressive symptoms and loneliness are described. In chapter 3 we discuss, with small focus groups of community-dwelling older persons, how health complaints are hindering in daily life. We also describe how older persons envision their own role in structuring their healthcare and what they expect from general practice concerning their general health, and specifically their hindering health complaints.

PART 2. APPROACHES TO THE DELIVERY OF PERSONALIZED HEALTHCARE

As described earlier, new questions arose from large trials regarding proactive care for older persons. These intriguing questions led to new hypothesis related to personalized healthcare for older persons in general practice. Three approaches are described in the second part of this thesis. Extensive input came from community-dwelling older persons themselves, since the first part of this thesis demonstrated the importance of involving older persons when shaping personalized healthcare.

1) Selecting the optimal target group

In order to provide the personalized care needed by the appropriate group of older persons, without falling short in care for other patients, it is needed to be able to select those older persons who are most likely to benefit from an intervention. It is not pragmatic to invite all community-dwelling older persons to a general practice for an extensive assessment of their health and well-being. However, in the past it has been proven difficult to select those older individuals that might benefit from intensive help and guidance from their general practice. It is also to be expected that not all older persons will be interested in participating. Keeping this in mind, it is interesting to explore possibilities regarding selection of older persons who

might benefit from interventions to improve or stabilize their functional status based on data available to the GP.

In chapter 4 we develop a model to predict a decline in functional status, using only variables that are easily available to a GP. This model may help in selecting older persons who are at risk of functional decline in the coming year and might therefore benefit from a GP intervention to prevent or reduce likely functional decline.

2) Targeting specific individual problems

Many older persons wish to be informed about their own health, although there is wide individual variation in this group (29). Involving them more in their personal healthcare could increase self-management and might have a beneficial impact on health (30). This can be particularly relevant when targeting individual problems. It is therefore relevant to explore the opinion of older persons on how to target individual problems.

In previous studies in this thesis older persons were asked about the hinder they experience from health complaints in daily life and how they cope with these problems, followed by the description of a predictive model designed to select older persons at risk for a decline in functional status. It can be imagined that 1) older persons could play a more active role in the selection of those who might benefit from an intervention and 2) in taking the first steps in goal setting and action planning. Based on ideas on this topic generated by the regional Older persons Advisory Board of the Leiden University Medical Center, we interviewed older participants about a screening questionnaire for identification of older persons with complex health problems. Chapter 5 describes how older persons value the results of a screening questionnaire and how they perceive their own role in handling these results.

3) Evaluation of individual goals

Setting goals is important: it provides motivation, sometimes even a sense of urgency, to accomplish something that you really want. In addition, a care-action-plan is valuable because it helps to prioritize problems and structure the steps to be taken, especially if several healthcare providers are involved (27). Generic evaluation methods might not be suitable for the evaluation of personalized care as provided when working with care-action-plans.

One promising method to evaluate personal care-action-plans is Goal Attainment Scaling. The use of Goal Attainment Scaling has been researched in the context of medical rehabilitation (and other medical disciplines) but not yet in general practice (31, 32). This method uses a scale to visualize the patient's current health condition, describes the steps towards a particular goal and evaluates whether this pre-defined goal has been attained (33). This approach makes it possible to evaluate those aspects that are of value to the patient, potentially making it a suitable evaluation method for care-action-plans and a way to further involve older persons in shaping their own healthcare. In chapter 6 we explore the feasibility

of Goal Attainment Scaling as an evaluation method for care-action-plans for community-dwelling older persons in general practice.

In the general discussion (chapter 7) the findings of this thesis are summarized and reflected on. Evidence-based recommendations for improvements in personalized healthcare in general practice for community-dwelling older persons are formulated.

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