



## Perceived control in health care: A conceptual model based on experiences of frail older adults



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### ABSTRACT

Frail older adults are increasingly encouraged to be in control of their health care, in Western societies. However, little is known about how they themselves perceive control in health care. Therefore, this study aims to investigate the concept of health care-related perceived control from the viewpoint of frail older adults. A qualitative interview study was conducted following a Grounded Theory approach. Thirty-two Dutch frail older adults, aged 65 and over, participated in 20 in-depth interviews ( $n = 20$ ) and three focus group discussions ( $n = 12$ ). Data were analysed according to techniques of coding and constant comparison. From this analysis constituting factors of perceived control emerged, providing elements of a conceptual model. Perceived control reflects the feeling or belief that health care is *under control*, which is constituted by five, either internal or external, factors: (I) self-confidence in organising professional and/or informal care, (II) self-confidence in health management in the home setting, (III) perceived support from people in the social network, (IV) perceived support from health care professionals and organisations, and (V) perceived support from (health care) infrastructure and services. Therefore, the concept does not only consist of people's own perceived efforts, but also includes the influence of external sources. Our conceptual model points out what external factors should be taken into consideration by health care professionals and policy makers when enhancing older people's perceived control. Moreover, it can serve as the basis for the development of a measurement instrument, to enable future quantitative research on health care-related perceived control among older adults.

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## Introduction

### Background

Due to the increase of life expectancy, and the baby boom generation entering their third life phase, Western societies undergo a rapid growth of the proportion of older adults (Knickman & Snell, 2002; Zweifel, Felder, & Meiers, 1999). Consequently, there will be growing numbers of older people who cope with multiple and/or chronic health conditions (De Bruin et al., 2012; World Health Organization, 2009) who likely require more extensive forms of health care (Eklund & Wilhelmson, 2009). To face up to this development governments of ageing populations need to adapt their health and care policies. A trend that can be observed is the rising focus of these governments on the encouragement of older adults to be in *control* of their health and health care (Angus & Reeve, 2006; Clark, 1987; Martin-Crawford, 1999; Roberts, 1999). In the Netherlands for instance, the current policy discourse stresses that older adults should function as independently as they possibly can (Da Roit, 2012).

Given this development, it is urgent to foster scientific research on the concept of *control* in health care among older adults, in particular among those who are frail. Often, these people use multiple types of care, where issues of collaboration and integration of care between different care providers, interactions between informal and professional caregivers, and the loss of privacy may create situations where maintaining control is both important to streamline care and also is harder to realise. However, up to now, there is only limited understanding of the conceptualisation of health care-related *control*. Especially, the perceptions of the target group are not investigated sufficiently.

This article addresses the concept of perceived control in relation to health care, from the viewpoint of frail older adults, covering various types of care and a variety of settings; in the private sphere as well as in the office of the professional. We focus on the constituting factors that form perceived control in health care among frail older adults, a conceptual model that summarises these factors, and the reflection on how these affect perceived control, as well as the role of perceived 'personal' control in this respect.

For our work, we chose to start from the concept of *perceived control*, because it is a neutral psychological term with a broad theoretical basis, encompassing both components of self-efficacy and locus of control (Skinner, 1996; Wallston, Wallston, Smith, & Dobbins, 1987). It refers to *the belief that one can determine one's internal states and behaviour, influence one's environment, and/or bring about desired outcomes* (Wallston et al., 1987, p. 5). We consider that its general theoretical basis is a good frame for the domain-specific concept of health care-related perceived control that we intend to explore, as we expect that control within the context of the health care process covers a wide repertoire of thoughts, actions, and evaluations of a diversity of situations in this process, to which elements of both self-efficacy and locus of control are applicable.

### Literature overview

Much has been written about the concept of *control* (Skinner, 1996; Walker, 2001; Wallston et al., 1987), as well

as about concepts like *mastery* (Pearlin & Schooler, 1978; Skaff, Pearlin, & Mullan, 1996; Younger, 1991), *self-efficacy* (Bandura, 1977), *locus of control* (Levenson, 1981), *empowerment* (Hage & Lorensen, 2005; Martin-Crawford, 1999; Zimmerman, 1995; Zimmerman & Rappaport, 1988), and *sense of agency* (Hitlin & Long, 2009). All of these are conceptually associated, but being used in different theoretical traditions, e.g. psychology (*mastery, control*), or anthropological work (*empowerment, agency*). However, many of these concepts have definitions with a strong theoretic and/or generalist fundament, and are mostly discussed in the context of rather broad domains, such as life, the life-course, or well-being.

The studies that specifically include the older population in this regard mostly investigated the course, the influential factors, and associated characteristics of control or control-related concepts. For example, Schieman and Turner (1998) found that higher age and disability were related to lower levels of *mastery*; and higher education levels were believed to predict greater *personal control* (Hitlin & Long, 2009). Moreover, Pearlin, Nguyen, Schieman, and Milkie (2007) noticed that extended education would indirectly influence the *life-course mastery* of older people 'through the greater occupational and financial opportunities' provided by education after high school (p. 173). Other authors indicated that although *mastery* is responsive to circumstances, it can also operate as a capacity (Skaff et al., 1996): it might buffer the impact of decrease in physical health on older people's well-being (Jonker, Comijs, Knipscheer, & Deeg, 2009), and it could buffer against the anxiety related to disability problems (Krokavcova et al., 2008). Furthermore, it was frequently reported that higher *mastery* levels are positively associated to physical and mental health outcomes, for example to lower risks of decline in functional ability (Kempen, Ranchor, Van Sonderen, Van Jaarsveld, & Sanderman, 2006), or to less depression (Krokavcova et al., 2008). Other researchers explained that a given level of *control* could be retained despite health decline; mainly through processes of selection, optimisation, and compensation (Baltes & Baltes, 1990) or through accommodative coping (Brandtstädter & Rothermund, 1994).

In relation to control in the health care setting specifically, authors often discussed the role of the doctor-patient relationship, by describing phenomena such as *shared decision-making* (Brody, 1980; Frosch & Kaplan, 1999), and *patient-centred approaches* in the medical practice (Mead & Bower, 2000; Rohrer, Wilshusen, Adamson, & Merry, 2008). Brody (1980) argued that whenever people are ill, less self-reliant, and need to depend on the doctor's decisions, this may undermine their sense of control and self-esteem, as well as their sense of dignity, which shows the importance of patient involvement in the care process. Indeed, some level of involvement was found to be important to many patients, based on data resulting from patient interviews or questionnaires (Bastiaens, Van Royen, Pavlic, Raposo, & Baker, 2007; Frosch & Kaplan, 1999). At the same time, however, there appears to be much variance between and within (older) patients concerning their wish to participate in medical decision-making: not all patients are equally willing to do so (Bastiaens et al., 2007; Brody, 1980; Frosch & Kaplan, 1999; Roberts, 1999). Generally, it was seen that if patients were more involved in their own care, they showed better health behaviours (Hochhalter, Song, Rush, Sklar, & Stevens, 2010) and improvement in control of chronic

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