Patient satisfaction in innovating integrated care for older persons : towards care with personal value

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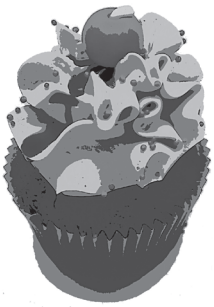
Chapter 1

General introduction



Medical care for older persons is changing. (1,2) This is partly a consequence of the challenges presented by changes in demography and society, which became apparent during the 20th century and are expected to continue. (3,4) These challenges apply at both a policy level and at the level of healthcare provision. Due to the increasing number and proportion of older persons, the challenges related to policy are mainly concerned with capacity and finance. (5) The challenges for the actual provision of health care is also related to capacity. In addition, this implies changes for daily practice, such as an increasing number of treatable chronic diseases within the same individual. There is also a shift to more attention for quality of life and comfort in the aging population; this is the ultimate goal and encompasses more than merely the absence of disease. (6,7) These changes have led to new care models and paradigm shifts which come together in the concept of 'person-centered, integrated care'. (8) This implies that new forms of cooperation are required within and between the medical and welfare domains, and between the professional and informal caregivers. (9)

In the Netherlands, the combination of policy and the wish of older persons to grow old in the community means that it is particularly in primary care that the challenges of an aging society are met. Traditionally the general practitioner (GP) was the sole coordinator of primary health care, as well as the gatekeeper for secondary health care. Nowadays, since the GP is no longer the only player in the provision of person-centered integrated care in the community, meeting the present challenges is now considered a team effort.

The case of Mr and Mrs P. (described below) illustrates the double meaning of changing care, in that it is not only the situation which has changed but that there is also an active process of changing care for the better, i.e. a continual progress. This is called innovation.

Changing care

Care in 1986

Mr and Mrs P. are a couple in their eighties, living in a village in the western part of the Netherlands. Mr P. (a retired accountant) suffers from diabetes and general vascular problems whereas Mrs P. is relatively fit physically but suffers from early symptoms of dementia. They live contentedly in the house where they raised their two children, happy with each other and the daily routine of their modest lifestyle. A domestic help (a lady who is not much younger than the couple) comes to clean the house, and help with the shopping and preparation of meals. Their children are well educated, have their own families and demanding careers, and live in different parts of the Netherlands. For Mr and Mrs P., their only activities outside the house are a weekly visit to the church and to the bridge club in the local community center. Although this routine has been followed for many years,

it was recently disrupted because Mr. P had to undergo amputation of an ischemic toe. He was admitted to hospital for a few days and then discharged home, but unable to move from his chair without help.

The village has three general practitioners (GPs) and Mr and Mrs P. have been patients of one of these GPs since he started his practice many years ago. Mr P. had been discharged on a Friday and, when the GP made a home visit on the following Monday, he encountered a distraught and squabbling couple. Due to the increased demands on Mrs P. it became apparent that her dementia had deteriorated to such an extent that she could no longer function adequately in the household. For example, yesterday she had put the kettle on to make tea but had become distracted and had left the gas burning. The GP has now planned a visit to coincide with a visit from the community nurse who has come to attend to the husband's foot wound. Their daughter is also present. Problems and practical solutions are discussed while sitting at the kitchen table, and actions are planned and allocated.

Care in 2017

Before Mr P.'s discharge, a social worker employed by the hospital contacts the village's GP medical center as well as a community social worker who is part of a social care team (*sociale wijk team*), to initiate the necessary home care. Wound care is initiated via a home nursing organization which is related to the same organization that the hospital belongs to. In the GP medical center, one of the five GPs has a discussion with the practice nurse who runs the diabetes and cardiovascular program, and also with the practice nurse who runs the geriatric care program. Since the diabetes/cardiovascular nurse only knows Mr P. from his visits to the practice for the respective prevention programs and the geriatric nurse has visited the couple at home in the past, and also because Mrs. P. has been diagnosed with dementia, it is decided that the geriatric nurse will follow-up the case. She plans a home visit to make an inventory of the care needs situation and to coordinate activities. She contacts the council social worker who has also visited the couple and plans a Skype conversation with the daughter. A care plan is made and discussed with the elderly care physician who regularly advises the GPs. It is decided to involve a dementia case manager, domestic care, 'meals on wheels', and to initiate an account in the digital case documentation & communication module. The couple has signed forms permitting their children, and all the caregivers involved, to use the module. The option of admitting one or both of the older persons to a nursing home is discussed; however, because it is not yet considered necessary, the decision is deferred. A visit by one of the GPs is planned to evaluate the situation with the couple.

Changes in care

In the 1980s, it was expected and common practice that, as the needs of an older couple or individual started presenting problems, the GP fulfilled a central role in organizing appropriate care. Most likely there would be an exchange between the GP, the older person(s) and their children and/or their neighbors, after which decisions would be made as to how best to solve the problems. Solutions could consist of practical actions, like arranging a lift with someone from the social club, cooking on electricity instead of gas, or regular visits to the grocery store with a volunteer, and having some shopping delivered at home. Financial actions might also be necessary, such as asking a local civil servant to help fill in forms and tax returns, or requesting a contribution from the church funds towards taxi costs. Medical actions could include starting or stopping therapies, possibly involving other (usually local) (para)medical professionals. Over time, the conclusion might be reached that procedures should be set in motion to obtain a place in the local residential care home. This was not a 'doom scenario' since it was often the location for many social activities, and both residents and staff knew each other and (some) were, literally, family. Medical caregivers, including the GP, continued seamlessly in the new setting. Satisfaction with the GP's contribution was sometimes expressed in the form of a chocolate letter at St Nicholas, or a bottle of wine at Christmas but, most often, in the form of the continuing relationship and process of tackling new questions together as they arose.

In 2018 the GP still plays a role in coordinating the medical care for older persons living in the community, but the care has become less exclusive. While the practical problems and solutions may not have changed greatly, the organization has. Many other professionals are included and the role of the informal caregivers has become formalized. The changed healthcare organization concept has been captured in the phrase 'person-centered, integrated care' and a paradigm shift has occurred from 'reacting as required' to 'proactive anticipation'. (10,11)

As an overall measure for the succes of the provided care, the concept 'value' has now become widely used. This combines the achieved outcomes of care and the costs of doing so. (12) In person-centered integrated care, the new care organization term 'value' therefore also includes the personal values of patients, since these partly determine both the achieved outcomes and the costs. These personal values are more consistent and have not changed substantially over time. For older persons, particularly qualitative studies consistently show the same personal values being prioritized, albeit under various names, e.g. social relations, functional ability and activities, security and health status. (13,14,15,16) These personal values influence the perception of changes in care.

The personal values of the immediately involved caregivers are also relevant when changing care. For example, GPs still define their role by the core values of being gener-

alist, person-centered and offering continuity of care. (17, 18) The degree to which these values remain intact influences their perceptions of changes.

The changes taking place in health care are partly a reaction to changes in society and views on disease and disability. Major changes are that there are more older persons who, while having a greater number of diagnosed and treatable chronic diseases, are increasingly wealthier and better educated and expect to stay active longer. (6,7,8,19). There is also a proportionately greater number of less-fortunate older persons with functional restrictions and (complex) care needs. (4) Due to a shift from a welfare state to a participation society and the accompanying changes in laws and regulations, many of the Dutch older persons with complex care needs who were previously cared for in sheltered residential facilities (care homes) are now living more or less independently in the community. (20,21) In the community the older persons, and their professional and informal caregivers, are confronted with the challenge of putting together an appropriate package of medical, social and domestic care. In the Dutch context this has to be performed within the framework of the three separate laws governing medical care and costs (Health Care Act), social care and participation (Social Care Act) and long-term care and disability (Long-Term Care Act). (22) The actual care is partly regulated at a national and partly at a municipal level. It is delivered by organizations and autonomous professionals financed from a mix of public and private funds via the three above-mentioned laws and out-of-pocket money from citizens. Informal caregivers are increasingly relied on to fill the gaps (23). Professional care organization has become more complicated through phenomena such as free market competition, task specialization, care centralization and interdisciplinary cooperation. (9,11,24,25) Combining these changes with the necessity to find solutions for rising healthcare costs has inspired influential care concepts such as 'value-based healthcare' and 'triple aim' which, in turn, have introduced new roles and procedures for policymakers, and care users and providers. (8,12,26,27)

Innovating care

As mentioned before, care change is partly driven by changes in society and context. Therefore, a conscious effort must be made to ensure the incorporation of both the individual and collective personal values of patients. Traditionally, at the individual level, the actual care was based on the available resources and the one-to-one interaction between physician and patient. Nowadays, the actual care is still partly determined by the one-to-one interaction between the caregiver and patient as it was in the past. Increasingly, however, it is also determined by protocols and standards leading to a selection of predetermined interventions created under the influence of evidence and policy, and delivered by multiple professionals. (28,29,30) The expression of the personal values of the patient in the actual care received remains vulnerable, as it was before. (31,32) Ensuring that 'An individual's specific health needs and desired health outcomes are the

driving force behind all healthcare decisions and quality measurements' is now called 'patient-centered care'. (33,34) Patient-centeredness, formerly largely dependent on the one-to-one relation between the patient and the caregiver (GP), is now also an organizational entity in care innovation. To achieve and ensure this, we depend on instruments such as shared decision-making at the individual level, and value determination at the collective level. (32)

A still relatively underdeveloped approach is to involve patients directly in the care innovation process, usually referred to as 'patient engagement'. (35) Experience and evidence is being developed with patient engagement varying from an advisory function in an organization through participation in decision-making. (36,37) This has the potential of truly putting the patient at the center of care development and bypassing a number of problems related to collecting and interpreting patient opinions and translating them to care design. Thus, while there are changes in progress at the various levels ranging from (inter) national policy, organization and financing and professional delivery, the voice of the patient needs to be expressed and heard at all levels. A practical question is: how can patient centeredness be incorporated into care improvement and innovation with personal value?

Towards care with personal value

This thesis focuses on combining the process of innovating care practice and the values of the older persons involved, by investigating patient satisfaction while innovating and implementing integrated primary care. We propose a role for patient satisfaction of older persons in the innovation and implementation of integrated care, thereby addressing the question as to how patient satisfaction can help the innovation of strategies and processes towards 'care with personal value'.

Description of used concepts

Integrated care is of particular importance to older persons with complex health problems. Since integrated care is person/patient-centered and its design and implementation should represent personal value, patient satisfaction is a relevant instrument and outcome. Since all these concepts are interrelated, these concepts are briefly described below.

Integrated care

There is no single definition of 'Integrated Care'. In her 2016 report for The King's Fund entitled 'Supporting integration through new roles and working across boundaries', Helen Gilburt refers to the definition used in a 2008 World Health Organization directive (9,38) and this definition is still valid today. Therefore, the following working definition of integrated care is proposed: '*The management and delivery of health services so that clients*

receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system'. This directive indicates that integrated care can mean different things to different people. For example: i) to the user, it can mean that the care is seamless, smooth and easy to navigate; ii) to providers it implies that separate services are provided, managed, financed and evaluated in relation to each other; iii) for professionals, it means that different (health) professions or disciplines/ specialties work together to provide joined-up services; and iv) at the management and policy level, it can mean that decisions on policies, financing, regulation and/or delivery are appropriately compartmentalized.

This definition (as well as its practical interpretations) emphasizes that integration of care must be based on the needs of the users. Perhaps the best expression of the 'patient-centeredness' of integrated care is offered by the title of the UK National Health Service consultation document (2012) on this subject: '*No decision about me without me*'. (39) Moreover, in his book on integrated care, Schrijvers goes further by adding to the WHO definition the following phrase '*...according to their needs, throughout their whole life and in continuous discussion with the patients*'. (10)

In their conceptual framework for integrative primary care Valentijn and colleagues show the full range of elements of horizontal and vertical integration around the person-centered focus. (11) The horizontal ranges from functional to normative while the vertical ranges from clinical to system.

Both the WHO definition and the framework of Valentijn and colleagues accentuate that the obligatory focus on the user/person optimally integrated care, involves many levels and expressions and its development can therefore follow various routes.

Patient satisfaction

Patient satisfaction is defined as an evaluation by the patient based on the fulfilment of expectations. (40,41) Satisfaction with the GP can be determined by asking the question 'How satisfied are you with your GP?' The responses can be quantified by requesting a score on a scale ranging from 0 to 10, or using a 5-point (Likert) scale ranging from very satisfied to very dissatisfied (with three intermediate choices).

The concept 'patient satisfaction' can be further understood by its historical development. In 1983 Gregory C. Pascoe wrote a review based on the literature on patient satisfaction in primary health entitled 'Evaluation and Program Planning'. He concluded that, although relevant as a predictor and indicator of care outcomes, additional (especially longitudinal) research was required. (42) In particular, the small effect sizes in the measurements of satisfaction were reported to be a problem.

In 1997, John Sitzia and Neil Wood published a review in Social Science & Medicine on patient satisfaction entitled 'Patient satisfaction: a review of issues and concepts'. They concluded that, possibly due to pressure from the rising consumerism in Western medi-

cal practice, more attention was paid to the measurement of satisfaction in management and professional terms as an audit tool, than to understanding the underlying meaning. (43) The authors suggested that more attention should be paid to dissatisfaction and a narrative approach should be applied to care expectations, and warned healthcare providers about a too optimistic interpretation of satisfaction responses.

Patient satisfaction with health care has an impact on patient outcomes, including treatment adherence and health behavior. (44-46) It is also argued that only patients themselves can evaluate the entire (especially chronic) care process and determine whether (or not) it provides worthwhile outcomes. (47) However, because patient satisfaction offers only a partial picture of care organization, it is not sufficient to use this as a design indicator and evaluator of care improvement. For example, patient satisfaction does not reflect the technical quality of care, but is strongly associated with the ratings of communication. (48) Moreover, the personal characteristics of patients and care providers (such as age and gender) also influence patient satisfaction. (49, 50)

A study published in 2010 in the British Medical Journal showed that 4.6% of the variance in the satisfaction rating of patients of their GPs was related to differences in the GP practices. (51) This prompted the discussion in the editorial section under the heading: 'Are measures of patient satisfaction hopelessly flawed?' The general conclusion was that this is not the case, but that the measures do need to be refined. (52)

Implementation

Implementation research is the study of methods to promote the systematic uptake of proven clinical treatments, practices, and organizational and management interventions into routine practice and, thereby, improve health (see homepage implementation science url: https://implementationscience.biomedcentral.com/).

Despite broad agreement on the evidence for the 'health improvement' effect of an intervention, in practice the required changes are not always made. This phenomenon has been described and solutions have been suggested in 'Crossing the quality Chasm' by Plsek. (53) Implementation can be seen as the combination of strategies and interventions aimed at bridging this chasm.

Confusion about the terminology is often present in implementation literature, because the same term might be used for various concepts (homonyms), and differing terms might be used to describe the same concept (synonyms). In this thesis, all the terms used are in accordance with the rationale that care innovation entails designing new care and promoting its uptake and dissemination in daily practice through a combination of interventions and strategies. Care innovation can consist of redesigning and adapting existing care, and the combined process of promoting uptake and dissemination can be called implementation. However, in practice, innovation and implementation are so closely related that they cannot be easily differentiated.

Complex health problems

An individual can have multiple health problems and this situation is more likely to occur in older persons. These problems can be categorized according to their consequences in the four domains of i) somatic, ii) functional, iii) psychological and iv) social functioning. Complex health problems can be defined as the accumulation and interaction of problems in multiple domains. In a research setting, as developed in the ISCOPE study, an individual is considered to have 'complex health problems' when he/she reports (or is found to have) problems in two or more of the four domains. In case of an increasing number of domains, an interaction of problems has a more than linear association with poor health and wellbeing outcomes, including increased use of care, and death. (54)

Aim and outline of this thesis

The overall aim of this thesis is to provide an evidence-based proposal for the incorporation of the opinions and values of older persons in the innovation of their GP care, by investigating patient satisfaction as an influencing factor in the innovation and implementation of integrated care.

The background projects

This thesis is based on two large research projects (for one of which the author was project leader), performed within the department of Public Health and Primary Care. Both projects took place in and around the city of Leiden between 2009 and 2013 as part of the National Program for Elderly Care.

The ISCOPE study

The overall aim of the Integrated Systematic Care for Older PErsons (ISCOPE) study was to assess, in general practice, the efficacy of a simple monitoring system for determination of the individual level of complexity of health problems and the composition and performance of a personalized care plan, as an operationalization of integrated care. In this project (led by J.W. Blom), a postal screening questionnaire, aimed at finding perceived problems in four domains (somatic, functional, psychological and social functioning) was sent to all persons aged 75 years and older in 59 primary care practices. (55) In 30 random intervention practices, the GPs and their practice nurses were trained in providing person-centered integrated care. This entailed making and performing an individual integrated care plan for a randomized selection of patients with perceived health problems in 3 or 4 of the four domains. In the control practices, patients received 'care as usual'. Participants in the intervention and control practices were visited by a research nurse at baseline, and again one year later, to collect demographic and clinical data as well as information on how they experienced the care.

The MOVIT project

The *Medischezorg Optimalisatie in Verzorgingshuizen Implementatie Traject* (MOVIT) project (Medical Care Optimalization in Care Homes Implementation project) was initiated in the region South Holland-north with the aim of developing a strategy for the implementation of improved integrated care for older persons throughout the entire region. In this project (led by A.J. Poot), a total of 29 local teams of GPs, nursing staff, pharmacists and elderly care physicians were formed, serving 33 of the 43 regional residential care homes. To improve care, these teams were individually coached and offered regional training in moving towards optimal person-centered integrated care for their residents. They prioritized and made improvements in inter-professional cooperation in the daily delivery of integrated care. The implementation process was described and all residents of the participating care homes were visited by a research nurse at the beginning and after (at least) one year of implementation to collect demographic, clinical, and care experience data.

Overview of this thesis

In this thesis, the first four studies contribute to the overall aim by providing evidence on patient characteristics and values, and patient satisfaction; the fifth study contributes by describing the position patient satisfaction can have within the real-life implementation of integrated care for older persons in the community.

Chapter 2 presents an investigation of the relationship between satisfaction and patient characteristics in the ISCOPE study; this study focuses on the association between the complexity of health problems and satisfaction. The aim is to better understand the seemingly contradictory finding that emerged from earlier studies, i.e. that increasing age is related to higher satisfaction while the age-related increase in morbidity is related to lower satisfaction.

Chapter 3 further explores the relation between the complexity of health problems and patient satisfaction, by examining changes in satisfaction levels during the implementation of integrated care in the ISCOPE study in relation to the perceived health state of the older persons.

Chapter 4 investigates the role that the doctor-patient relationship, as perceived by the older persons, plays in their level of satisfaction with the GP in the MOVIT study.

Chapter 5 examines the changes in perceptions of aspects of integrated care among older persons and GPs during the implementation of integrated care in the MOVIT project. Investigating these differences in parallel serves to highlight the differences in values.

Chapter 6 describes how, retrospectively, using descriptive frameworks a matrix was developed to capture the complex process of the pragmatic real-life implementation of

the MOVIT project. On reflection, implementation of MOVIT reveals the role that patient satisfaction could have played in this process.

Chapter 7 discusses the evidence provided by the studies in the previous chapters concerning the role of patient satisfaction. The evidence that emerged is placed in the context of the available literature. After reflecting on the experiences gained by performing the MOVIT and ISCOPE projects, a proposal is formulated as to how patient satisfaction can be used in the implementation of integrated care. Finally, a brief description is given of the studies and activities that are planned as a continuation of the work presented in this thesis.

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