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van Loon, Miriam Suzanne

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Understanding Quality of Life in Older Adults Living at Home

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Care and Capability

Understanding Quality of Life in Older Adults Living at Home

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door

Miriam Suzanne van Loon

geboren te Amsterdam

Promotoren: prof.dr. G.A.M. Widdershoven
prof.dr. R.W.J.G. Ostelo

Copromotoren: dr. J.E. Bosmans
dr. S. Metselaar

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CHAPTER 1

General Introduction

CHAPTER 1

Introduction

Older adults live at home longer than before, and in the upcoming years, the number of older adults living at home will further increase (SCP, 2019). In this setting, older adults are often confronted with difficulties in their daily life which affect their quality of life (QoL), such as functional limitations and/or lack of social contacts. The opportunities to engage in various activities and the control over one's life often decrease because of these difficulties. Care services delivered at home can support older adults in maintaining activities in life that are important to older adults, and may increase their autonomy, contributing to their QoL.

This thesis seeks to establish an in-depth understanding of what is important for the QoL of older adults living at home receiving professional care services, and how to assess outcomes of care in terms of QoL. Specifically, this thesis focuses on the ASCOT and its relevance for assessing QoL of older adults in the Netherlands. The ASCOT is an instrument developed in the UK, and was designed to evaluate outcomes of social care services by capturing information about an individual's QoL in various domains (Netten et al., 2012). The developers of the ASCOT were inspired by the Capability Approach (CA). The CA is developed by Amartya Sen and Martha Nussbaum and the central idea is that capabilities are essential for the well-being – i.e. human flourishing, or 'the good life' – of both individuals and societies, and that by protecting and restoring capabilities, well-being will increase (Nussbaum & Sen, 1993). Capabilities express what people are able to do and be. The focus is not on what people actually do, but what they can chose to do and pursue based on what they regard as meaningful and valuable.

Still, questions remain. To what extent are the core principles of the CA included in the ASCOT? And do the ASCOT domains capture all relevant aspects of QoL from the perspective of older adults living at home (in Western society)? In what way and to what extent can professional care services contribute to QoL of older adults living at home? These questions will be explored theoretically and empirically, combining insights from philosophical theory – with the CA as normative framework - and empirical qualitative studies into the views and experiences of older adults themselves.

Older adults living at home in the Netherlands

Older adults increasingly live independently and receive care in their own home. The Dutch population is aging, meaning that the percentage of older adults in the general population is rising; currently there are 1,3 million adults above the age of 75, and this number is expected to rise to 2,5 million in 2040 (RPL, 2019). Of all people aged 75 and over, 92% live at home and almost 25% of these people use support and care (SCP, 2019). In the Netherlands, 44% of the health care budget is spent on older adults and this is expected to rise to 59% in 2040 (RIVM, 2020; Wouterse et al, 2016). Thus, the demand for care is expected to increase in the future.

In this thesis, the focus is on the evaluation of QoL in older adults living at home and how care provided by professionals may affect their QoL. Older adults often use a combination of medical care and other types of services. Care services received by older adults living at home include mental health services, home care, day care, transport services, prevention, physical activities, meal services, physiotherapy and social programs.

Because of the increasing number of older adults living at home who receive care services and decreasing budgets, determining relevant outcomes of care, providing care of good quality to older adults, and evaluating of its outcomes, are increasingly important. Additionally, determining 'value for money' can help to decide about the reimbursement of care services (Sorenson et al., 2008). 'Value for money' is assessed in health economics, by relating the outcomes of care services to the costs of these services (Johnston, 2004). The most important outcome in such assessments is QoL, which is generally measured with self-reported instruments. The instruments most frequently used in health economics now focus on health-related QoL. In the next section, we will briefly address this approach.

Evaluation of care outcomes

In economic evaluations, costs and effects of different interventions are compared, providing information about the value for money these interventions provide (Drummond et al., 2015). The aim of these evaluations is to support policy makers in deciding which interventions to reimburse and which not (ibid). The goal of policy makers is often to maximize benefits and use available resources efficiently (ibid). In the care sector, the goal is on maintaining well-being. In the cure sector, the primary goal of interventions is to achieve health gains (Willemstein et al., 2009).

In economic evaluations, these health gains are preferably expressed as quality adjusted life years (QALY). The QALY combines life expectancy and health-related QoL in one measure. Health-related QoL instruments such as the EQ-5D and the SF-36 are used to measure the health status of participants (EuroQoL Group, 1990). The EQ-5D-5L, for example, consists of five domains; mobility; self-care; usual activities, pain/discomfort, and anxiety/depression each scored on a 5 point Likert scale (Herdman et al, 2011). In the Netherlands, care for older adults at home is also evaluated with the EQ-5D in terms of QoL (Mangen et al., 2017).

Older adults living at home often use care services. Interventions in the care sector focus on reducing effects of impairment on people's daily lives and on maintaining well-being and include disability care, nursing, home care services and psychiatric care (Willemstein et al., 2009). The primary goal of care is thus not improving health, but improving other aspects of QoL. Because of these differences in focus and intended outcomes between cure and care services, different instruments are needed to evaluate outcomes of interventions.

Several instruments have been developed to measure outcomes in long-term care from a broader perspective than health alone, incorporating domains of well-being that are specifically important for the long-term care sector (Willemstein et al. 2009). The ASCOT and the ICECAP are two well-known instruments that can be used to measure outcomes of care services not directly aimed at improving health (Van Leeuwen, 2015). The ASCOT is specifically designed to evaluate outcomes of social care and captures information about an individual's social care-related QoL in eight domains. The ICECAP measure for Older people (ICECAP-O) is a measure specifically developed for use in economic evaluations of health and social care interventions for older adults (Flynn et al., 2011).

The ASCOT has been shown to have face and construct validity (Malley et al., 2012) and to be more responsive to effects of home care compared to the EQ-5D (Forder et al., 2011). The ASCOT was translated and validated into Dutch (Van Leeuwen, 2015a), and was shown to be associated with self-perceived QOL, mastery, and client-centeredness of home care (Van Leeuwen, 2015b). This thesis focusses on reflection on and the usability of the ASCOT-NL in the Dutch context.

The ASCOT

The Adult Social Care Outcomes Toolkit (ASCOT) was developed to measure QoL as an outcome of social care in the UK. The ASCOT includes eight domains: control over daily life, personal cleanliness and comfort, food and drink, personal safety, social participation and involvement, occupation, accommodation cleanliness, and comfort and dignity (Netten et al., 2012). The toolkit consists of different measures, including a four-level self-report assessment that measures QoL from the perspective of the care receiver. This assessment tool is called the ASCOT SCT-4. When referring to the ASCOT in this thesis, the SCT-4 is meant.

Within each ASCOT domain, respondents can choose out of four statements the statement that best describes their situation. For example, the control domain is covered by the question *'Which of the following statements best describes how much control you have over your daily life?'*. The options range from *'I have as much control as I want'*, to *'adequate control'*, *'some control, but not enough'* to *'I have no control over my daily life'*. The ASCOT can be used to support outcomes-based management in a variety of organizations; central government, local government, social care providers' (https://www.pssru.ac.uk/ascot/). In addition, several researchers have suggested to use the ASCOT in economic evaluation of social care services (Bulamu et al., 2015, Makai et al., 2014, Van Leeuwen et al., 2015b) and to determine the effectiveness of social care interventions or policy (Callaghan et al., 2017, Bauer et al. 2017).

This thesis is part of a larger project aiming to adapt the ASCOT to the Dutch setting, focusing on older adults living at home. Differences in context between the UK and the Dutch setting can influence the relevance of QoL domains. The extent to which this is true needs to be investigated. Additionally, preference weights have been estimated for the Dutch population (Van Leeuwen et al., s*ubmitted*). This part of the project is not included in this thesis, where the focus is on (philosophical) theoretical and qualitative (empirical) questions, as described in the next sections.

The Capability Approach

As mentioned above, the ASCOT is based on the Capability Approach (CA). In the CA, questions of (social) justice are central; how should we divide resources? When evaluating the well-being of a nation, economic growth is usually used as indicator (Sen, 2009). The CA challenges monetary evaluations by insisting on the importance of capabilities, that is what people are actually able to do and be (Nussbaum, 2003). Living is seen as a set of 'functionings', for instance 'being nourished' (Nussbaum & Sen, 1993). One may not have the opportunity to be nourished, or have the opportunity, but choose not to use it (for instance, in a case of hunger strike). The CA emphasizes the importance of giving (a diverse group of) people both the opportunity for functioning and the possibility to choose. Capability is the *freedom* to do or to be what one values. The main question for evaluating QoL is: are people actually able to do and be what they have reason to value? According to the CA, evaluations should focus on equality of capabilities.

The CA provides a new paradigm, a way of thinking about normative issues, that can be used for a range of evaluations, focusing on information to evaluate for example individual well-being and social policies (Robeyns, 2005). Because of Sen's background as economist, his work on the capability approach fits with economic reasoning and is adaptable to quantitative empirical operationalization and measurement (Robeyns, 2005). Some questions remain about the operationalization of certain aspects (Robeyns, 2006). For example, how to select relevant capabilities – should we use a list as defined by experts, or rather by engaging stakeholders in a democratic process to determine capabilities? Should capabilities be maximized individually, for society as a whole, or should we use another principle of aggregation such as providing a minimum capability level?

In health economics, evaluating care in terms of capabilities means we should evaluate QoL outcomes in terms of what people are able to do with the services they receive; rather than only valuing happiness as relevant outcome, as is done in welfare economics (Coast et al., 2008B) - or health-related QoL in health economics. The CA is increasingly incorporated in new instruments (Coast et al., 2008A, Coast et al., 2015, Lorgelly et al., 2010, Alkire, 2005, Chiappero-Martinetti, 2008).

The CA can help to include aspects such as freedom that are often overlooked in other, more traditional approaches, to well-being (Chapero-Martinette et al., 2015). The move/transition away from achieved functionings towards the freedom that a person has in their lives to achieve aspects of well-being is important because people's ability to be or do something may be of value even if they choose not to take up that capability (Coast et al., 2015). Also, this 'broader focus may better capture benefits from interventions' (Coast et al., 2015). Additionally, frameworks used in gerontological research are criticized for their inability to account for diversity and differences in engaging with experiences of aging (Gopinath, 2018), and for focusing on health-related aspects of aging (Mitra et al., 2020, Dunn, 2018). The CA can be used as framework to put the values and diversity of people at the center and move away from a health focused view (Gopinath, 2018, Meijering et al., 2019). In this way, the CA can help to understand what really matters to older adults who receive care.

Aim and research questions thesis

The overall aim of this thesis is to establish an in-depth understanding of what is important for the QoL (QoL) of older adults living at home receiving professional care services, and how to assess outcomes of care in terms of QoL using the CA and focusing on the ASCOT. How can we understand QoL in later life from the perspective of older adults living at home? This thesis specifically aims to answer the following questions:

1) How can the ASCOT be understood from the philosophical perspective of the CA?
2) What are important aspects of QoL from the perspective of older adults living at home?
3) How can care services contribute to QoL in older adults living at home?
4) How can important aspects of QoL from the perspective of older adults be addressed in QoL instruments?

Methodology

In this thesis, different methodologies are combined to understand QoL in older adults living at home. Specifically, philosophical analysis is combined with qualitative empirical research. This approach is in line with and inspired by an empirical ethics approach as described by Davies et al (2015): a collection of 'methodologies that seek to use empirical data about stakeholder values, attitudes, beliefs and experiences to inform normative ethical theorizing'. In this way, the question how to understand QoL in older adults living at home is explored in 'a way that draws on the strengths of both philosophical and empirical analysis' (ibid).

The goal of the philosophical analysis is to gain further insight in the CA and its operationalization in the ASCOT. The goal of the qualitative research is to understand the world from the perspective of the participants, assuming that multiple meanings and understandings of a phenomenon are likely to co-exist (Green & Thorogood, 2018 p. 16). This assumption is in line with the assumptions of the CA that people are diverse, and have different ideas about the good life and about what entails QoL. The following table describes the specific methods used in each of the studies:

	Methods
Chapter 2	Philosophical analysis: comparing the CA and the ASCOT
Chapter 3	Qualitative research: thematic synthesis of interview data
Chapter 4	Qualitative research: interview study
Chapter 6	Qualitative research: interview and focus group study

Table 1: The methods used in the chapters

Outline of this thesis

To answer the research questions, various studies were conducted, which are described in the consecutive chapters of this thesis. In short, the following studies will be reported:

In **Chapter 2** the main characteristics of the CA are discussed, as well as the main assumptions of the ASCOT. A philosophical analysis of the ASCOT as operationalization of the CA is provided, focusing on three main characteristics; QoL evaluation should not be on functioning but on freedom of choice; evaluation should be critical about adaptive preferences; evaluation should address more domains than health.

Chapter 3 presents a thematic synthesis review on the meaning of QoL to older adults. Data from empirical qualitative studies are analyzed to categorize QoL domains from the perspective of older adults living a home.

In **Chapter 4** the results of an empirical study on the experiences of older people living at home concerning the contribution of care services to their QoL are presented, using the ASCOT and the thematic review as framework. Three types of care services - medical services, social support services and support in daily living - are taken into account.

Chapter 5 presents a new tool, the Extended Quality of Life Tool (EQLT), based on results of the thematic review.

In **Chapter 6** the results of an empirical study on the views of stakeholders on the relevance of the EQLT for practice, as well as facilitators and barriers for implementation are presented.

Chapter 7 discusses the findings of the studies presented in this thesis, followed by a reflection on issues related to the use of domains in measuring QoL and questions about the distribution of resources and the provision of care in the community. Also, an overview is provided of the strengths, weaknesses of this thesis, and recommendations are formulated with regard to future research and organization of care.

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CHAPTER 2

Quality of life in a broader perspective: *Does ASCOT reflect the capability approach?*

Van Loon, M.S., Van Leeuwen, K.M., Ostelo, R.W.J.G., Bosmans, J.E., Widdershoven , G.A.M. (2017)

Quality of Life Research, 1-9

Abstract

Purpose

Economic evaluation of services and interventions in care services tends to focus on quality of life(QoL) based on health-related measures such as EQ5D, with a major focus on health and functioning. The Capability Approach (CA) provides an alternative framework for measuring QoL and challenges some of the conventional issues in the current practice of measurement of QoL. The Adult Social Care Outcomes Toolkit (ASCOT) aims to measure social care-related QoL in a broad sense. This article investigates whether and, if so, how the ASCOT addresses issues put on the agenda by the CA.

Methods

Literature analysis concerning theoretical assumptions and arguments of CA and ASCOT.

Results

The Capability Approach (CA) puts three issues on the agenda regarding QoL. First, the focus of evaluation should not be on functioning, but on freedom of choice. Second, evaluation should be critical about adaptive preferences, which entail that people lower expectations in situations of limited possibilities. Third, evaluation should not only address health, but also other domains of life. Our analysis shows that freedom of choice is reflected in the response option 'as I want' in the ASCOT questionnaire. The problem of adaptive preferences is countered in the ASCOT by developing a standard based on preferences of the general population. Third, the ASCOT contains several domains of life.

Conclusions

We conclude that the CA and the ASCOT contribute to the discussion on QoL, and that the ASCOT operationalizes core assumptions of the CA, translating the issues raised by the CA in a practical way.

Keywords

Quality of life · ASCOT · Capability approach · Economic evaluation

Introduction

Societies are aging and the number of people living with a chronic disease is rising, resulting in a growing need for care services for older adults [1]. This increase in the demand for healthcare has led to an enormous increase in (health) care costs while the resources available are limited. Therefore, (health)care decision makers (e.g., policymakers and service providers) need to decide on how to spend these scarce resources best, for example, in decisions for national reimbursement and local commissioning. By doing so, decision makers aim to maximize the health benefits within their allocated budget [2]. Information to inform these decisions is often obtained from economic evaluations in which the costs and effects of two or more interventions are being compared. Such allocation decisions are generally taken using information from scientific studies in which the costs and effects of two or more interventions are being compared. Such studies are referred to as economic evaluations. Currently, economic evaluations focus on Quality Adjusted Life Years (QALYs) as the primary outcome [3, 4] in which both quality of life (QoL) and life gains are included.

The QALY measures length and QoL based on a health-related QoL measure such as the EuroQol-5D (EQ-5D). Yet, many interventions, treatments, or health care services lead to an improvement in outcomes otherthan health alone [2, 3, 5, 6; p. 1194, 5, 6]. For example, increasing mobility by providing a walker can influence someone's ability to go outdoors, increasing a person's feeling of being in control and autonomous, and enabling her to have a social life. In this way, many aspects of QoL can be influenced by an intervention aimed, not at changing health, but at supporting physical, psychological, and social functioning. QALYs are likely to underestimate the outcomes of such care interventions [7, 8], as many care receivers have chronic diseases in which improvements in health-related QoL such as operationalized in the EQ-5D are very unlikely, and often these domains are not specifically targeted by these services [2, 9]. Therefore, the standard of relevant outcomes needs to be broadened when evaluating interventions in social care, and we need to redefine what we consider as 'value for money' within this setting.

In care services for older adults, outcomes are now often evaluated on the basis of health-related QoL measures. The foundation of the QALY-framework, focusing on maximization of health, lies within the extra-welfarism approach in health economics [10, 11]. This approach might not always be in line with the goals and philosophy of these kinds of services. A promising alternative to implement in the evaluation of outcomes of services in long-term care for older adults can be the capability approach (CA), shifting the focus towards QoL in a broader sense [12].

The CA is a political, philosophical, and economical theory which presents a view on QoL, that goes beyond health. In the CA, well-being is the core concept. QoL, or, more generally, well-being, is assumed to consist of a variety of capabilities—we should evaluate what people are able to do and who they are able to be [13]. The focus is on enabling people to do the things they want to do. Since people are different and have diverse needs, the freedom to be able to live the life one wants and to do what one values is central in the CA. The CA has been implemented widely in developmental economy and proven to be a successful approach in this area [14]. In care services for older adults, the CA may provide a valuable framework for measuring QoL that shifts the focus from a narrow conception of health to a broader conception, and fits the lifeworld of receivers of this type of care [15–21]. For many care receivers, regaining health is not the most important goal, maintaining QoL, however is relevant to most of them [17, 19].

In recent years, different questionnaires with the purpose of evaluating outcomes of (health)care have been developed based on the CA, such as the OCAP-18, ICECAP, and the ASCOT [22]. In this article, we focus on the Adult Social Care Outcomes Toolkit (ASCOT), a measure that aims to measure QoL from a broader perspective than health alone which is partly based on the CA and now widely used in the United Kingdom for the evaluation of social care services [23, 24].

In this paper, we will address the following question: To what extent are issues raised by the CA concerning (the measurement of) QoL addressed by the ASCOT? We will first consider three main issues put on the agenda by the CA. Next, we will investigate whether and how the ASCOT addresses these issues. In the discussion, we will reflect on the findings and mention some topics that need further consideration.

Methods

This paper is part of a larger project studying QoL in older adults, analyzing the philosophical background of ASCOT and applying the questionnaire to the Dutch context as an alternative to EQ-5D in economic evaluations. For this paper, theoretical literature on the CA was analyzed, focusing on the arguments for using this approach as an alternative for current ways of measuring QoL. Literature of the main authors of the CA was studied, and further literature was selected using a snow-ball method, collecting articles through references. Since much has been written about CA theory, with diverse goals, a selection was made on the basis of the purpose of this article, that is to investigate how the issues put on the agenda by the CA concerning measuring QoL are addressed in the ASCOT. We thus do not present a systematic overview of the CA literature, but specifically want to elaborate on the perspective of the CA on measuring QoL and its relation to the ASCOT. In our project the focus is specifically on older adults, but ASCOT and the CA can also be relevant for a broader population.

Central issues of the CA

The CA has been developed within political philosophy, as a reaction to existing theories of justice, especially utilitarian welfarism and justice as equal distribution of resources. In utilitarian welfarism, 'goodness' is assessed in terms of subjective utility, or happiness. In Rawls' Theory of Justice, the main claim is that justice requires an equal distribution of resources [25]. Sen, one of the founders of the CA argues in his Tanner Lectures 'Equality of What?' that neither utility, nor resources should be the focus of justice [26]. Rather, we should focus on people's capability to achieve functionings [14]. According to Sen, welfarism is too much focused on happiness, disregarding people's reflective valuations [27; p. 18]. Sen considers the focus in Rawls' distributive justice on resources people receive, equally narrow. We should evaluate well-being, defined in the CA as what people can do with these resources. There are major differences in individual abilities to convert resources into capabilities. People with disabilities might require more resources (e.g., a wheelchair, or more money to buy certain tools) to attain a certain level of capability (e.g., mobility) than others. Thus for Sen, income (a common operationalization of resources in economics) is not automatically well-being, because people use resources differently. Therefore, measuring resources is too limited.

In the CA, capabilities are central. Capabilities are defined as 'the alternative combinations of functionings the person can achieve, and from which he or she can choose one collection' [13; p. 21]. Living is seen as combination of these 'doings and beings' and QoL is to be assessed in terms of the 'capability to achieve valuable functionings' [13; p. 21]. In the following sections, three main issues of the CA relevant to evaluation of care services will be elaborated. The issues regard the importance of freedom and choice, the need to be critical of adaptive preferences, which entail that people lower their expectations, because they adapt to deteriorated circumstances, and the need to take into account several relevant domains of life.

Freedom and choice

Sen emphasizes the relevance of freedom and choice [14]. Freedom is valuable because 'it gives us more opportunity to pursue our objectives.' Moreover, the 'process of choice itself' is important [14; p. 228]. People should be able to live the life they want to live, and have the ability to choose certain functionings. Starving and fasting imply the same functioning—not eating—but the person who fasts still has the capability to eat, whereas the starving person has not [14]. A central idea of the CA is that having certain capabilities is fundamental for QoL and that, by protecting and restoring peoples' capabilities, well-being will increase [13, 14]. Care services may, for example, protect and restore people's QoL by providing support in everyday life activities which enables them to choose/realize certain functionings (e.g., physical therapy can support mobility, and in this way improves the capabilities of a person by providing her more options, or day-care activities can enable people to meet others, and provides more options for social relationships). The CA takes into account human diversity. The focus on freedom and choice in the CA hosts diversity of people with different 'life objectives,' backgrounds, opportunities, and conversion factors. The CA is a liberal framework which tries to avoid paternalism by focusing on freedom and choice, rather than stating certain functionings as important for everyone [28, 29]. QoL is different for everyone [29]. Capability, and not functioning, is seen as the correct political goal by capability theorists [28, 30; p. 101]. Physical handicaps can mean that people require different kinds of services to achieve a certain capability [30]. Also, if the same capabilities are present, people may choose different functionings, related to what they find valuable in living their lives [14].

People have different abilities to convert resources into capabilities. A person unable to walk requires more resources to be able to move in an environment, to compensate for this disadvantage. Therefore, according to the CA, in evaluations of well-being outcomes, we should measure whether people are able to do what they would like to be able to do instead of the services they receive or how happy they are [30]. Do they have options to choose from functionings they value? If not, we should create the circumstances to enable them to choose valuable things. In her version of the CA, Nussbaum [31] argues that society should enable people to fulfill certain basic capabilities such as being able to be nourished and educated; we should evaluate if the conditions for individual capabilities are met and protect and restore individual capabilities.

Overcoming adaptive preferences

Sen [14, 24] criticizes welfarism and argues that utility overemphasizes ‘mental and emotional responses to commodities (resources) and characteristics of commodities and not enough on what they enable you to do’ [32; p. 51]. The CA argues against measuring so-called ‘adaptive preferences’ [31; p. 34]. Being in a certain situation can influence a person’s experienced happiness and expectations of what is possible. Patients with severe medical conditions, for example, often lower their expectations of what life can bring [14, 30]. Even in a state of severe physical distress, patients may still consider their health as fine according to their lowered standards. When people are isolated, they can accommodate and feel that there is no need for more social contact. However, this does not mean that their situation cannot or should not be improved; care services are still needed to support and foster their QoL. Measuring the level of well-being in terms of utility might not grasp unjust circumstances, since expectations may have been adapted to the current, disadvantaged situation [14, 27, 32]. Therefore, an evaluation that focuses only on subjective mental metrics is insufficient without considering whether that matches with what a neutral observer would perceive as their objective circumstances. An external standard of well-being is needed in order to judge whether a situation requires improvement [14, 28]. Such an external standard may, however, be at odds with the emphasis on personal choice discussed in the previous section. We will go into this tension in the “Discussion.”

Multiple domains

The CA argues that evaluations of well-being should take into account multiple domains. According to Sen [27] we have to select certain relevant capabilities/functionings dependent on the setting, and attach weights, in order to make a QoL evaluation (p. 25). Nussbaum [31] constructed a list of Central Human Capabilities (CHCs), incorporating the moral entitlements of every human being. According to Nussbaum, people need a certain threshold level of CHCs, to lead a dignified human life and to flourish [31]. Nussbaum distinguishes ten CHCs: life; bodily health; bodily integrity; senses, imagination, thought; emotions; practical reason; affiliations; other species; play; control over one's environment (and being able to live one's own life) [31; pp. 41–42]. Sen is critical of making a universal list of capabilities, because, he argues, different sets will be relevant to different groups and in distinct settings [33; pp. 157–160]. Moreover, according to him, making a list disregards the liberal nature of the CA, since what contributes to 'quality of life' is determined by others than the people themselves. Sen does not provide concrete suggestions for relevant capabilities, but states that for each context 'some democratic process and public reason should be involved' [25, 33; p. 356]. Democratic processes of reasoning are crucial to select relevant capabilities, and decide which capabilities we have 'reason to value,' because 'what we may value is very diverse' [14; pp. 231–233]. In a pluralistic society, people disagree about values, have different ideas about which aspects of life contribute to QoL. His view is that through a process of reasoning, values and ideas about what QoL entails, can be made explicit and be made the object of deliberation. We should investigate for each particular context which capabilities are relevant.

Capabilities can be specified by empirical research as argued by several authors [29, 32, 34], either to construct for each context an index of relevant capabilities (Sen's version), or to concretize the general list of Nussbaum's CHC in a certain context. Qualitative techniques can be used for the selection of functionings and for determining their importance [34]. When QoL is defined in terms of a variety of domains, weights should be attached to determine the importance of each domain in a specific context. This attachment of weights to different domains has to be 'done in terms of explicit evaluations, drawing on the prevailing values in a given society' [34; p. 25]. There is discussion about who should decide what values are and how weighs should be attached [8, 30, 35, 36]. The CA does not provide straightforward answers to these questions and the theory is operationalized in different ways [29, 37, 38].

The ASCOT

The ASCOT was developed for measuring QoL, focusing on the goals of social care services. Social care services aim to provide support in basic functionings, such as nourishment and personal hygiene [39], and are, therefore, concerned with reducing the effect of impairment on people's daily life [40; p. 1]. During later development phases of ASCOT, the notion of capability was introduced, referring to recent policies aspiring to 'broaden[ing] opportunities for people with disabilities and developing 'independence', 'choice' and 'control'' [39; p. 1]. The presupposition behind the reference to capabilities is that service users are expected to value an increase of freedom and flexibility as outcome of services [39]. The ASCOT connects to capability theory and to more general societal developments by focusing on what social care receivers are able to do, on their capabilities, rather than on impairment and limitations. Since people have different needs (and wants), the produced value of a service varies per person [41; p. 3]. The ASCOT aims to measure these divergent outcomes [23, 39, 41].

The ASCOT toolbox consists of several instruments and can be used for evaluation of a wide range of services and settings. In this paper, we focus on the 4-level self-completion tool (SCT4) questionnaire[1] [39, 40]. ASCOT SCT4 assesses 8 different domains of QoL: (1) control over daily life, (2) personal cleanliness and comfort, (3) food and drink, (4) personal safety, (5) social participation and involvement, (6) occupation, (7) accommodation cleanliness and comfort, and (8) dignity. All domains have 4 response options; the first response option represents the ideal situation and the last one represents the worst imaginable state. An exemplary question for the 'social participation and involvement' domain is shown in Fig. 1.

Freedom and choice

In the ASCOT, it is assumed that some basic functionings are important for everyone: 'although preferences might differ, it is hard to imagine that any person is not better off if they are fed, clothed and sheltered than not' [40; p. 8]. Preferences for more complex functionings, however, can differ more substantially between people. Social contact, for example, can be less important for some people than for other people [40]. Therefore, especially in complex functionings, the potential to function is important, which indicates that capability should be addressed when measuring well-being.

In the SCT4 version, the notion of freedom of choice as a crucial aspect of capabilities is reflected in the response option 'as I want' [39]. This response option of SCT4 represents an ideal situation of full capability indicating that people are not restricted in the level they want to achieve, and the three lower options represent more basic functionings, indicating care needs [24, 39]. Moreover, a specificdomain is included which focuses on having freedom to choose important issues in life, namely 'control over daily life' [24, 39]. Netten et al. [24] argue that it is important to measure 'the full range from the very fundamental level where functioning levels are so low they could lead to mental and physical health implications, through to 'capability' states, in which people have real choice' [24].

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[1] The full ASCOT SCT-4 questionnaire can be requested at http:// www.pssru.ac.uk/ ascot/instruments.php.

Thinking about how much contact you've had with people you like, which of the following statements best describes your social situation?

- I have as much social contact as I want with people I like
- I have adequate social contact with people
- I have some social contact with people, but not enough
- I have little social contact with people and feel socially isolated

Fig. 1 Exemplary question of ASCOT

Overcoming adaptive preferences

In the ASCOT, the possibility of adaptive preferences is addressed in three ways. First, the ASCOT is based on a standard of basic functionings, the domains in the questionnaire. Some functioning states can be judged to be unacceptable by society (e.g., malnourishment), and a standard facilitates the argument that certain functioning states are too low [28, 39; p. 2]. Second, in completing the ASCOT respondents are encouraged to reflect upon their preferences by including 'as I want' response option. Is their situation ideal, or is there room for improvement? Third, for the calculation of a weighted total score the valuation of the different domains is based on the judgment (preferences) of situations by people from the broader society (see "Multiple domains"). Although the ASCOT does not take adaptive preferences for granted, they are not regarded as intrinsically wrong [24]. Coping is considered positive, since social care can support people's adaptation to changed circumstances, for example, by helping people to reduce the effects of impairment on people's daily lives [24]. However, we should not conclude, based on measuring adapted preferences, that a person's situation cannot be improved.

Multiple domains

Domains in the ASCOT have been taken from a previous project in which relevant domains of well-being in older adults were obtained from discussion with experts in the field, focusing on the question: what are the aims of social care services? [40] Additionally, the team drew on a contemporaneous large-scale qualitative project that examined how social care users define social care outcomes, using focus groups and interviews. The domains identified in this study fed into the final specification of the ASCOT domains [24]. The domains in the ASCOT are broader than current healthrelated QoL measures, for example, the EQ-5D which measures health and mobility as important domains. Domains in the ASCOT like (1) control over daily life, (4) personal safety, (5) social participation and involvement, and (8) dignity are concepts that go beyond health and mobility.

In the ASCOT, for each level within a domain, set weights have been estimated.

The weights for domains were developed through various studies, and the actual weights were developed by Netten et al. [24, 41]. Techniques used to establish preference weights for the eight domains are best–worst scaling (BWS) methods in combination with time-trade-off (TTO) methods [24] with members of the general population and social care service users. The analysis showed that there are 'no substantive' differences in preferences between service users and the general population [24]. The final model is based on preferences of '1000 members of the general population' [24].

Discussion

In this section, we will compare the CA and the ASCOT on the three issues mentioned before and mention some aspects which require further investigation. The main recommendations that we distilled from theoretical analyses of the CA [13, 14, 28, 29] are (1) we should be aware of diversity in people and thereby the diversity regarding personal freedom and choice; (2) we should be aware of the fact that people tend to adapt to their situation and (3) we should take into account multiple domains when measuring QoL, specified for different contexts and target groups. In this article, we focus on a comparison with ASCOT, but these recommendations are relevant for other capability measures too.

Freedom and choice

The CA underlines that people should have the freedom to choose between various functionings [14, 29]. Operationalizing freedom is a central issue in capability literature debate on this topic [22, 29]. In the ASCOT, the importance of freedom and choice is taken into consideration by including 'as I want' in the response options, as well as adding a 'control' domain [24, 27]. These elements in the ASCOT reflect the notions of freedom and choice in the CA. Yet, some topics need further consideration. In the first place, it may be discussed whether 'as I want' properly addresses the issue of freedom. Does the clause 'as I want' motivate the respondent to actually reflect and value the current situation, or does it merely lead to an indication of being content? Empirical clinimetrical research [42] indicates that there are significant differences in autonomy and control (as measured by the CASP subscale—a scale measuring control and autonomy) between the top two options of each ASCOT domain ('as much as I want' versus 'adequate'). Equally there are significant differences in CASP subscale scores between each level of the control domain. This would suggest that the difference in wording between the top two options for each ASCOT domain is reflecting control and autonomy, at least as it is described by the CASP subscale. Other research indicates that capabilities can indeed be self-reported; participants explained to understand the capability concept as 'capacity' and something they 'could do.' These empirical studies suggest including 'as I want' could encourage respondents to reflect on their capabilities

[43; p. 119].

Within each domain, respondents have the freedom to determine their own choices, by valuing their own situation by judging the situations within a domain. The domains are always the same in ASCOT, restricting people in determining what QoL entails. Some domains might be less relevant for some service users (they might not care for social contact), and those important to some may not be included in the current list (e.g., spirituality). However, for most of the domains, one can hardly doubt the relevance. It is difficult to imagine that persons are not better off if they are fed, clothed, and sheltered than not.

Overcoming adaptive preferences

In current economic evaluations of health care, usually indirect utility instruments such as the EQ-5D are used [3, 44]. Participants indicate their health status using a questionnaire consisting of several QoL domains and a pre-specified set of weights is used to value each health status, based on preferences of the general population [44]. In the ASCOT, taking into account adaptive preferences is an important topic [24, 39]. The instrument aims to measure QoL in reference to a standard. In order to determine the standard, the results of social care professionals (for determining which domains are important) and the general public (for determining weights) are used. In this respect, the ASCOT follows the line of the CA [39]. Yet, making a standard list is problematic, as it assumes that QoL is the same for every person, and consists of specific capabilities regardless of individual values [28]. This leads to a tension in the CA approach; the idea is to be open for different conceptions of QoL but in order to be able to compare well-being outcomes between various persons, fixed domains are needed. An alternative to account for diversity might be measurement scales where respondents can define their own outcome domains such as Schedule for the Evaluation of Individual Quality of Life (SEIQol) [45]. Although this might account for diversity in people's conception of QoL, adaptation complicates interpersonal comparison, hindering its use in economic evaluations.

As the ASCOT SCT-4 is a self-completion questionnaire, respondents evaluate their own situation, based on individual reflection. This approach has the advantage that respondents make their own judgment, and that other people do not make this judgment for them. Yet, this also gives room for individual interpretation, which may be influenced by adaptation to the situation [12, 14]. The answer options are broadly defined, and, as mentioned before, the clause 'as I want' can be interpreted in various ways. Thus, adaptive preferences are not fully excluded. This might not be problematic per se. As argued by various authors [30, 46, 47], it is good that people adapt to their situation. Adapting means people cope with deteriorating conditions [48]. The ASCOT team suggests that in order to judge whether adaptation is problematic or not, a more 'objective' expert could judge a person's capability set [24]. This could be an experienced professional, a proxy, family, or informal caregivers. However, in the CA theory it is assumed that individuals should have the freedom to choose between functionings [14]. The issue of measurement of adaptation is currently debated within the capability literature, since it is a recurring theme in operationalizing CA for measurement purposes [28, 47, 49, 50]. We believe that a possible solution might be an intersubjective approach, combining a subjective element (the respondents own evaluation) with a more objective list (including set domains, developed in empirical research, and evaluation by other people). For example, in the ASCOT care home version, data are triangulated obtained from trained observers, residents, and staff/family. In this way, multiple perspectives are combined. Such an approach is however more time consuming (and costly).

Multiple domains

In the ASCOT, QoL consists of multiple domains, in line with the CA. The domains of the ASCOT are also congruent with both the examples mentioned by Sen, and the list of central human capabilities proposed by Nussbaum [14, 31]. The latter does, however, entail wider elements which are not addressed in the ASCOT. It may be further discussed whether these capabilities should be the object of social care interventions. QoL may encompass domains which are currently not covered by the ASCOT, or domains specific to certain contexts or countries. Systematic reviews in specific target groups to analyze what QoL entails and what should be measured for these groups are recommended. This might be addressed by organizing processes of deliberation on QoL, involving stakeholders, especially older people or other care receivers themselves, in line with Sen's idea [14].

In these empirical processes of deliberation, supported by qualitative research, for example, in focus groups, wellknown problems of democratic processes, such as the power of the majority should be countered [29]. It is possible that people disagree on relevant domains [38]. The majority can outweigh the opinions of minorities on including certain capabilities [29]. In this way, the majority may decide what the good life is, not based on the quality of arguments, but on quantity. It is important to prevent 'ethics by opinion poll' [51]. Thus, including stakeholders requires careful procedures to counteract a system of voting and create conditions for an open dialogue between various parties involved. In empirical ethics, qualitative methods have been developed to include the perspectives of stakeholders [52, 53]. These methods entail in-depth interviews with stakeholders, and further exploration of the results of the analysis of these interviews in focus groups, both homogeneous groups, in which for instance healthcare professionals, patients, and family discuss issues raised in the interviews among themselves, and heterogeneous focus groups, in which various stakeholders exchange experiences and views to better understand each other's perspective and jointly develop new shared insights. Such methods might be helpful to further contextualize QoL measurements.

Conclusion

The CA is relevant for the evaluation of care services, shifting the focus from health-related QoL to a broader definition. The ASCOT can be regarded as an example of a broad measure of QoL, evaluating the outcomes of care services on more domains than health.

The CA puts three central issues on the agenda. The first is the need to focus on freedom and choice, and to pay attention to diversity in what people need, want, and can do with services. The second is the need to be critical about adaptive preferences, since poor conditions can give rise to lowered expectations. The third is the need to take into account that QoL consists of multiple domains. In general, these issues are addressed in the ASCOT. Thus, it is a promising instrument to evaluate long-term care services from the perspective of human capabilities.

Some aspects require further attention in future research. The first is the question whether the option 'as I want' and the domain of control over daily life in the ASCOT are adequate operationalizations of the notion of freedom in the CA. Does the sentence 'as I want' stimulate reflection on values in the way in which this is meant by the CA? In developing QoL questionnaires, it is important that instruments measure several domains and this measurement about QoL states is partly subjective (self-reporting, 'open' response options) and partly objective (fixed domains and weighting). More attention for diversity in questionnaires seems warranted to account for differences in personal needs and wishes of respondents. Furthermore, the influence of this personal weighting in the context of cost-effectiveness should be explored. The second is related to adaptation. Although one should be critical about adaptation to situations which can be improved, adaptation may not be fully prevented, and even regarded as positive in a situation in which one's physical abilities are diminishing. How to determine whether and when adaptation is acceptable, and even desirable? Here, an intersubjective approach might be useful, going beyond subjective and objective measures. Finally, the determination of domains and levels of capabilities requires attention. How to involve stakeholders in processes of deliberation, and organize democratic ways of answering the question which aspects of QoL are relevant in present society, and should be supported by care services? Developers of questionnaires should be aware of the needs and wishes of specific groups, and design methods for involving them in dialogical way. These issues for further research are not easily addressed. Yet, the CA and the ASCOT contribute to the discussion on QoL by raising awareness of the importance of these topics and suggesting pathways for further investigation.

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Compliance with ethical standards

Conflict of interest

All authors declare that they have no conflict of interest. This project is in collaboration with the ASCOT-UK group and the goal of our projects is to develop the Dutch version of ASCOT.

Ethical approval

This article does not contain any studies with human participants performed by any of the authors.

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CHAPTER 3

What does quality of life mean to older adults?

A thematic synthesis

Van Leeuwen, K.M., Van Loon, M.S., Van Nes, F.A., Bosmans, J.E., De Vet, H.C.W., Ket, J.C.F., Widdershoven, G.A.M., Ostelo, R.W.J.G. (2019)

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Abstract

Background

Consideration of older adults' quality of life (QoL) is becoming increasingly important in the evaluation, quality improvement and allocation of health and social care services. While numerous definitions and theories of QoL have been proposed, an overall synthesis of the perspective of older adults themselves is lacking.

Methods

Qualitative studies were identified in PubMed, Ebsco/Psycinfo and Ebsco/CINAHL, through a search on 28 November 2018. Articles needed to meet all of the following criteria: (i) focus on perceptions of QoL, (ii) older adults living at home as main participants, (iii) use of qualitative methodology, (iv) conducted in a Western country and (v) published in English (vi) not focused on specific patient groups. A thematic synthesis was conducted of the selected studies, using the complete 'findings/results' sections from the papers.

Results

We included 48 qualitative studies representing the views of more than 3,400 older adults living at home in 11 Western countries. The QoL aspects identified in the synthesis were categorized into nine QoL domains: autonomy, role and activity, health perception, relationships, attitude and adaptation, emotional comfort, spirituality, home and neighbourhood, and financial security. The results showed that although different domains can be distinguished, these are also strongly connected.

Conclusion

QoL can be expressed in a number of domains and related subthemes that are important for older adults living at home. The findings further support that the concept of QoL should be seen as a dynamic web of intertwined domains.

Introduction

The need for care services for older adults living at home will increase in the coming years because of the ageing population and deinstitutionalisation [1–3]. More and more older adults will age in their own home and the majority of them has one or more chronic disorders [4, 5]. For many of these disorders, cure is not an option. However, care is required to manage these disorders and to provide assistance with daily tasks in order to enable older adults to age at home. Care and support are provided by informal carers as well as various formal care services like rehabilitation, nursing care at home, day care, mental health and general practice care [6, 7].

At the same time, care providers are confronted with care reforms, budget cuts and increasing regulations for national and local commissioning and audit procedures [8]. As a result, the accountability of care services becomes increasingly important and there is a need to establish the value of such services. One way to determine this value is by assessing the outcomes achieved at the client level [9]. Maintenance of QoL is one the most important outcomes of care services for older adults. Several international action plans on ageing endorse the importance of QoL [10–13] and international interest in the measurement of QoL of older adults is growing [14–17].

It is, however, not evident how QoL should be defined or how it should be assessed. The debate about the definition of QoL is conducted among researchers from various disciplines and overlaps with explorations of the concepts successful ageing, subjective well-being, life satisfaction and happiness [18]. A taxonomy of the conceptual development of QoL shows that a large set of QoL frameworks exist, and from this set it was concluded that "*QoL is inherently a dynamic, multi-level and complex concept, reflecting objective, subjective, macro-societal, and micro-individual, positive and negative influences which interact together*" ([19], p.46).

While numerous definitions and theories of QoL have been proposed, a systematic overview of the opinion of older adults themselves is missing. Knowing what older adults themselves find important in life, is necessary to align the goals of care services to their expectations. Also, knowing what quality of life is from the perspective of older adults themselves is necessary for assessing the content validity of existing QoL measures. Qualitative studies can help researchers and decision makers to understand what QoL means to older adults, and a considerable number of such studies has been done. However, these studies are largely neglected, which may be due to the fact that each of these studies has been done in a particular setting with a particular study population and particular point of view [20, 21].

In order to assemble a more comprehensive picture of QoL, the findings from multiple qualitative studies can be combined in a synthesis that provides a range and depth of meanings, experiences, and perspectives of participants across contexts [22]. The larger scope and rigor of a synthesis compared to an individual study also means that there is a greater potential to influence policy and inform practice [20, 23–26]. A recent systematic overview, including all relevant qualitative studies on QoL from the perspective of older adults, is lacking. Earlier reviews did not (exclusively) focus on qualitative research [19], or were not systematic and included only a limited number of studies [18].A method that is considered appropriate to aggregate findings from a large number of qualitative studies is the thematic synthesis approach [22, 24, 26–28]. This approach uses thematic analysis techniques to bring together and integrate the findings of multiple qualitative studies by identifying the main, recurrent or most important themes [26]. The aim of the current review is to synthesize the findings of qualitative studies that explored what QoL means to older adults living at home.

Methods

Search strategy

A review protocol was developed according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA)-statement (www.prisma-statement.org). PubMed, Ebsco/PsycInfo and Ebsco/CINAHL were searched from inception up to 28 November 2018 (by KMvL and JCFK). The following terms were used (including synonyms and closely related words) as index terms or free-text words: 'aged' and 'quality of life' or 'satisfaction' and 'narration' or 'understanding' and 'qualitative research' or 'focus groups'. The full search strategies for all databases can be found in the Supplementary Information (S1 File). Duplicate articles were excluded. All languages were accepted.

Selection criteria

For inclusion in the review, articles needed to meet all of the following criteria: (1) focus on perceptions of QoL, (2) include older adults living at home as the main participants, (3) use of qualitative methodology, (4) conducted in a Western country, (5) published in English and (6) not focussed on specific patient groups. In order to avoid omitting research of potential value to the synthesis, qualitative methodology (criterion 3) was broadly operationalized as the use of open questions and a description of the findings in words rather than numbers [29]. Criterion 4 and 5 were used in order to keep the number of papers manageable. There was no restriction to publication year. Exclusion criteria were: participants from specific patient populations such as diabetes or cancer patients (as these studies tend to focus on disease-specific aspects of QoL), and participants living in residential facilities such as care homes, nursing homes or retirement homes.

Selection procedure

The references from the different databases were imported into Mendeley [30], after which duplicates were removed. Each of two authors (KMvL and MSvL) screened half of the titles and abstracts to exclude articles that did not meet the inclusion criteria. In case of doubt, the article was included in the selection of papers potentially relevant to the review. Next, full texts were retrieved and further assessed for eligibility by both KMvL and MSvL, independently from each other. Disagreements were discussed by the two authors until consensus was reached. Reference lists of included studies were checked to identify additional relevant studies for the synthesis.

Since QoL is a dynamic and not strictly defined concept, we decided to use an inclusive policy regarding the focus on QoL. Researchers from different disciplines and backgrounds may have used various terms to describe aspects that contribute to quality to the life of older adults. Therefore, we included also studies using terms such as 'life satisfaction', 'successful aging' 'living well', 'well-being', and determined topical similarity by looking at the research purpose, the questions asked and the type of findings presented [21].

Data extraction

All papers were read several times before and during analysis by two review authors (KMvL and MSvL). The following study characteristics were extracted by KMvL: information about the sample and sampling procedure, information about the data collection method and the methodological orientation or data analysis approach, information about the focus of the study and questions asked to participants, information about the theoretical frameworks that guided the development of questions or interpretation of findings, and the main conclusions from the authors.

The complete 'results' or 'findings' sections from the studies were seen as data for this review and entered verbatim into a Microsoft Excel database by KMvL or MSvL, simultaneously dividing the text into smaller but meaningful fragments. These fragments thus included quotes from participants as well as text written by the primary studies' authors such as interpretations and clarifications of quotes, descriptions of participants' responses and descriptions of the context in which responses were given. The labels, categories or themes under which the authors described the data were noted next to the specific fragments. Data from discussion sections (including more theoretical interpretations) was not extracted.

Thematic analysis

We adopted the three stages of the analysis in thematic synthesis as described by Thomas & Harden [26]: free coding of the findings of primary studies; organisation of these free codes into related areas to construct descriptive themes; and development of analytical themes. The stages overlapped to some degree.

For the first stage of analysis, free coding, two authors (KMvL and MSvL) independently coded each extracted fragment according to its meaning and content. Within the fragments we identified QoL aspects (elements of older adults' life that affected their QoL), and used these as codes to label the fragments. Each fragment was coded using at least one label, but more than one was possible as fragments could contain descriptions of multiple QoL aspects. The labels we used were primarily based on (description of) quotes of the participants rather than on labels used by the authors in the primary studies, since the categorization of similar quotes could be different, given that these authors had various disciplinary backgrounds or theoretical frameworks. After coding the first three papers, and subsequently after every two papers, KMvL and MSvL met to compare their codes, making sure that interpretations of codes were aligned. During the process of analysis, the coding scheme was discussed extensively and continuously, and adjusted and complemented if necessary. After 11 papers the definitions of codes were clear to both authors and only few new codes came up, so the remaining papers were divided between KMvL and MSvL to code them. Occasional new codes or updates of definitions were discussed, and applied to previously coded fragments.

In the second stage of analysis the free codes of all identified QoL aspects were combined or grouped in a total of 60 descriptive themes. In the third stage these were further categorised by KMvL and MSvL into 16 analytical themes after looking for similarities and differences between the descriptive themes and the fragments belonging to each descriptive theme. Each analytical theme was described by several subthemes. One analytical theme for example was 'life philosophy', which included fragments about 'enjoying small things', 'staying positive', 'being interested' etc. A draft summary of the findings across the studies was written for each of the 16 analytical themes by KMvL or MSvL, focusing primarily on the quotes of older adults in the fragments belonging to that theme. We subsequently reread the summaries and discussed the meaning of each theme and its relations with other themes. Disagreement or uncertainties were discussed and interpretations of the themes were validated with four of the other authors (JEB, RWJGO, FAvN, GAMW). During this stage, we identified similarities and strong connections between some of the analytical themes and decided to combine some of them. This final step resulted in 9 QoL domains described by 38 subthemes that cover all the QoL aspects we identified in the extracted fragements.

Finally, we examined to which extent the 9 QoL domains were covered in the data. We determined the coverage of a domain in each paper by looking at the total length of fragments that we categorized under that particular domain. Four 'coverage' categories were used: 'not mentioned', 'briefly mentioned' (in one to three sentences), 'discussed' (in a larger paragraph), and 'discussed extensively' (in more than one paragraph). We cross tabulated the papers and the domains showing the coverage in the cells, in order to get an overview of how consistently the QoL domains were mentioned across settings and subgroups of older adults.

Results

The searches initially resulted in a total of 15,758 references, following elimination of duplicates this number was reduced to 12,257 references. After screening of abstracts, 12,139 papers were excluded because they did not meet the inclusion criteria. From the remaining 118 papers, full texts were retrieved and eligibility was determined by two authors. One paper was added via reference checking. Eventually it was agreed that 48 papers met our inclusion criteria. The details of the selection process are shown in Fig 1.

Reviewed studies

Characteristics and conclusions of the 48 included studies are displayed in Table 1. The studies together included more than 3,400 older adults, who were living in 11 different countries.

Most studies were conducted in the US (13 studies), Sweden (8 studies), the UK (7 studies) or Canada (7 studies). The samples were very diverse, including among others older widowed women living in rural and remote areas in Australia [31],

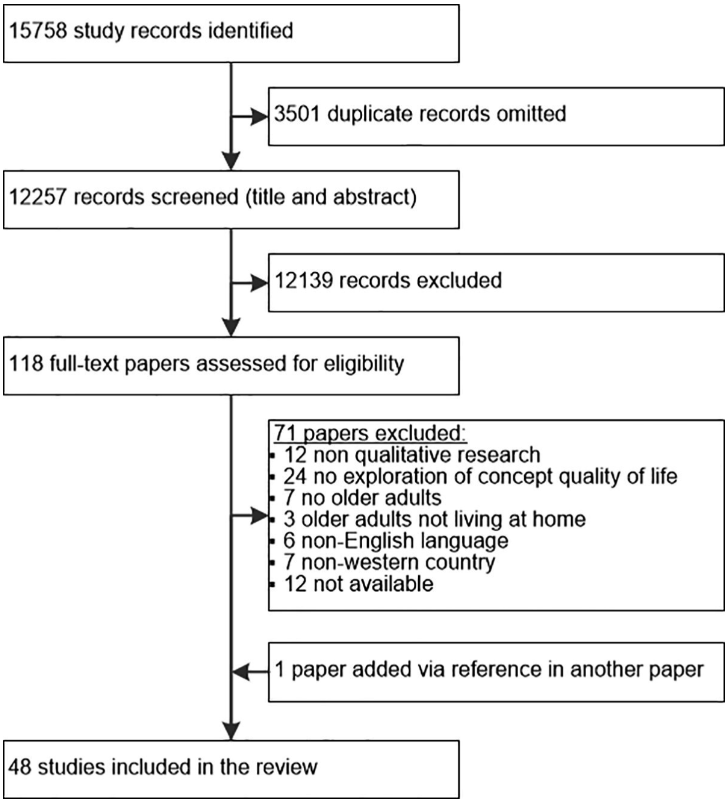

Fig 1. Flowchart for selecting studies.

foster grandparents from Missouri (US) [32], older adults receiving palliative care in Sweden [33] and older men residing in London (UK) [34]. Participants were most frequently recruited via care organisations and senior centres or via their participation in epidemiological cohort studies. In almost all studies either half of the participants or a majority of the participants was female. Reported mean ages ranged from 71 to 91 years. The most commonly reported reasons for excluding participants were minor or major cognitive impairment, not being able to communicate in a specific language, or less specific reasons for not being able to participate or give informed consent.

Nine studies used focus groups or group interviews for data collection, five studies were based on open questions in a survey, and the remaining studies used individual interviews. The method of analysis consisted of content analysis or thematic coding, grounded theory analysis, and phenomenological or hermeneutical approaches.

Quality of life domains

We categorized the QoL aspects included in the extracted data into nine QoL domains: 'Health perception', 'Autonomy', 'Role and activity', 'Relationships', 'Attitude and adaptation', 'Emotional comfort', 'Spirituality', 'Home and neighbourhood', and 'Financial security'. An overview of the domains and subthemes is shown in Table 2. Each domain is further described and illustrated with quotes in the section below.

Health perception: Feeling healthy and not limited by your physical condition.

Health is mentioned as a necessary and sometimes even paramount element of QoL, eg: "*Above all, being healthy is the most important thing to have quality of life, the rest comes as an extra*" ([37], p.76). The perception of health was partly determined by the extent to which older adults felt fit and active or suffered from **physical, mental and cognitive disorders**. Troublesome symptoms, functional limitations and side effects from medication (such as poor balance, poor memory, pain, vision loss and fatigue) significantly decreased their QoL. *"Blindness is the one thing and then I was diagnosed with diabetes and then I had a heart operation. I'm still walking around and I still enjoy playing music so in that way I'm blessed but in other ways I'm not…" (*[77], p.944).

The perception of health is also determined by the **point of reference** used; older adults compare their health for instance often with that of others their age. The experience of health was therefore described as a relative phenomenon [36]: it is experienced and evaluated according to what one finds reasonable to expect, given one's age, history, medical condition, and social situation. For example, some older adults find declining ability frustrating *"I cannot do what I did ten years ago, and I get very angry… I get disgusted with myself"* ([42], p.934), while others were more accepting, saying that other people are worse off, or that pain, fatigue and illness were to be expected in old age. This explains why older adults may still perceive their health as 'good' despite chronic diseases,

Table 1. Characteristics of studies included in synthesis.

Paper: Author year [ref] (country)	**Sample and recruitment**	**Data collection method**	**Data analysis approach / methodological orientation**	**Focus of study**	**(Example of) questions asked to participants**	**Theoretical perspectives / frameworks that guided development of questions, codes or interpretation of findings**	**Conclusion**
Aberg 2005 [35] **(Sweden)**	15 older adults (80+) with a diagnosed need of rehabilitation during a hospital admission, purposefully selected at the geriatric clinic	Qualitative interviews on three occasions: at the geriatric clinic, and 1 month and 6 months after discharge	Thematic framework approach	Factors perceived as important for life satisfaction	What is important for you to be able to do in order to be satisfied with life?	NR	Three themes emerged as important for life satisfaction: activity, independence and adaptation
Andersson 2008[33] **(Sweden)**	17 older adults (75+) receiving municipal help and care and having a life- threatening disease or receivingpalliative care, purposefully selected by nurses working in municipalities	Qualitative interviews with a narrative approach	Content analysis	Experience of aspects that bring about a good life in the last phase of life	Tell about your life situation especially what brought about a good life	NR	The experience was interpreted to be *Turning inwards to come to peace with the past, the present and approaching death while being trapped by health complaints*. Six categories embraced the experience of aspects that constitute a good life in the last phase of life: maintaining dignity, enjoying small things, feelings of "being at home", being in the hands of others, trying to adjust, still being important for other people and completing life while facing death.
Bergland 2007 [36] **(Norway)**	282 older women (75 +) randomly selected from census files local authorities, participating in a community-based randomized study	Writing down the answer on one open ended question	Grounded theory	What QoL means	Write down what the phrase QoL means to you		Significant dimensions of the quality of life highlighted in the current study relate to holism, a pragmatic approach of health, relationships, participation and activity, belonging and the social environment, and personal values. Feelings of continuity, power, and the ability to grasp meaning in their lives are cornerstones of the quality of life for elderly women.

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Table 1. (Continued)

Paper: Author year [ref] (country)	**Sample and recruitment**	**Data collection method**	**Data analysis approach / methodological orientation**	**Focus of study**	**(Example of) questions asked to participants**	**Theoretical perspectives / frameworks that guided development of questions, codes or interpretation of findings**	**Conclusion**
Bernardo 2014 [37] **(Portugal)**	48 older adults (65+) selected from a health care centre registry	Semi-structured interviews	Content analysis	Perceptions of QoL	NR	Categories were created by taking consulted literature about QoL definitions into account	The older people who participated in the study described QoL as being healthy, having peace, living in harmony, feeling happy, being satisfied with life, and keeping oneself busy, whether with hobbies, volunteer service or work. It also meant preserving interpersonal relationships and receiving support from family, friends and neighbours.
Black 2015 [38] **(US)**	1) 51 community-dwelling older adults (65+), purposively sampled in a range of residential and recreational community venues 2) 216 community-dwelling older adults (65+), recruited via a range of media and in community venues with high volumes of older adult presence	1) Focus groups and 2) open-ended surveys	Content analysis	What matters most in the context of everyday community life	What matters most as you live your daily life in this community?	A reality-oriented perspective	Findings suggest five key themes, all underscoring the prominence of the continuation of self as one ages in the community: (1) Preserving and promoting health and well-being; (2) continuing living arrangement and lifestyle; (3) maintaining autonomy and independence; (4) engaging in meaningful social opportunities; and (5) accommodating community assets.
Borglin 2005 [39] **(Sweden)**	11 independent older adults (80+) living in their own home, purposively sampled via connections of the author	In-depth interviews	Interpretative hermeneutic phenomenological method	Experience and meaning of QoL	I am interested to hear about your thoughts, feelings, and experience of the good life/QoL and how this has influenced you.	NR	QoL in old age meant a preserved self and meaning in existence. The areas contributing to the experience of QoL were: life values, recollection of previous life, activities, health, significant others, material wealth, and home.

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Table 1. (Continued)

Paper: Author year [ref] (country)	**Sample and recruitment**	**Data collection method**	**Data analysis approach / methodological orientation**	**Focus of study**	**(Example of) questions asked to participants**	**Theoretical perspectives / frameworks that guided development of questions, codes or interpretation of findings**	**Conclusion**
Bowling 2003 [40] **(United Kingdom)**	999 older adults (65 +) living at home, randomly selected from British household addresses: The Quality of Life Survey	Face-to-face interview survey with open-ended questions	Content analysis	Definitions of and priorities for a good QoL	Thinking about your life as a whole, what is it that makes your life good/bad? What single thing would improve your QoL?	NR	Social relationships and health were judged to be the most important areas.
Bowling 2007 [41] **(United Kingdom)**	1) 999 older adults (65+) living at home, randomly selected from British household addresses: The Quality of Life Survey 2) subsample of 80 respondents for the validation of subthemes in in-depth interviews (purposively selected)	Mixed methods including open-ended survey and in-depth interviews	1) thematic categorisation 2) grounded hermeneutic methods + constant comparison	Main attributes that gave life quality (and underlying reasons)	Elicitation of respondent's own descriptions of QoL (good and bad), their prioritisation of these things and how QoL can be improved	NR	The main reasons underlying the things people said gave their lives quality focused predominantly on: the freedom to do the things like they wanted to do without restriction; pleasure, enjoyment and satisfaction with life; mental harmony; social attachment; social roles; feeling secure.
Bryant 2001 [42] **(US)**	22 community-dwelling older HMO-members (60+) with a history of chronic conditions and high utilization, randomly selected from a group whose reported perceived health differed from that predicted by a regression model	Semi-structured interviews	Grounded theory-type methods	Factors that contribute to healthy aging	What they themselves believe describes and contributes to health/ well-being	NR	To these older people health meant going and doing something meaningful, which required four components: something worthwhile to do, balance between abilities and challenges, appropriate external resources, and personal attitudinal characteristics
Bryant 2004 [43] **(Canada)**	Older adults in 7 participating cities, more information NR	Focus groups and individual interviews	Each of the seven project sites carried out its own data analysis.	Perceptions of the influence upon their QoL	What are the events or situations that have diminished/ improved quality of life for you or for people living in your community? What things that affect your life could be influenced by governments?	Each of the seven project sites used their own framework, for example the concept of distributive justice, or an ecological approach	There was agreement across all locations as to the importance to seniors' QoL of the following: access to information, health care, housing, income security, safety and security, social contacts and networks, and transportation.

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Table 1. (Continued)

Paper: Author year [ref] (country)	**Sample and recruitment**	**Data collection method**	**Data analysis approach / methodological orientation**	**Focus of study**	**(Example of) questions asked to participants**	**Theoretical perspectives / frameworks that guided development of questions, codes or interpretation of findings**	**Conclusion**
Carr 2017 [44] **(Canada)**	42 community dwelling older adults (65+), purposefully sampled from a local Center for Seniors, a senior's walking program, a senior's exercise program, a local church and through snowball sampling	6 focus groups and 16 semi-structured interviews	Naturalistic inquiry	Factors that contribute to successful aging during different decades of older adulthood	What does it mean to age successfully? What do you think contributes to successful aging?	NR	Primary themes related to successful aging (staying healthy, maintaining an active engagement in life, keeping a positive outlook on life) were agreed upon by participants in all decades of older adulthood, while age-based differences existed among secondary themes.
Cherry 2013 [45] **(US)**	90 older adults (60+), drawn from the Louisiana Healthy Aging Study	Survey with 3 open ended questions	Content analysis consistent with grounded theory	Perceptions of longevity and successful aging	What is the key to living a long life? What do you look forward to the most? What advice or words of wisdom would you have for a young person today?	NR	Three major themes: (1) maintaining physical, mental and relational well-being; (2) living a healthy life; and (3) living a faithful life
Dionigi 2011 [46] **(Canada)**	21 older women (75+) with varying physical activity levels, purposeful selected from a seniors' centre and retirement community	In-depth interviews	Inductive analysis; narrative content analysis	Meaning of 'old' and 'successful aging'	Do you have any hobbies or regular activities that you enjoy? What does successful aging mean to you?	Stories were interpreted in the context of biomedical, psychosocial, and biographical approaches to successful aging	The findings particularly highlighted the multiple ways women make sense of their own aging and the extent to which their stories resist and reproduce cultural discourses of aging and gender. It appears that the more active the women, the more their definitions reflected key concepts in the biomedical model.
Douma, 2015 [47] **(the Netherlands)**	66 older adults (65+), recruited through local gatekeepers	Interviews with 'participant-generated word-clouds'	Content analysis	Subjective well-being in older age	Write down all aspects that you consider to be important for personal well-being	NR	15 domains were found based on participants' conceptions of subjective wellbeing. The multidimensional domains of social life, activities, health, and space and place were most important.

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Table 1. (Continued)

Paper: Author year [ref] (country)	**Sample and recruitment**	**Data collection method**	**Data analysis approach / methodological orientation**	**Focus of study**	**(Example of) questions asked to participants**	**Theoretical perspectives / frameworks that guided development of questions, codes or interpretation of findings**	**Conclusion**
Duay 2006 [48] **(US)**	18 healthy senior adults (59+) familiar to the researchers (convenience sampling)	Interviews with open ended questions	Constant comparative method	Perceptions about successful aging and the role of learning in the process of adapting to age-related changes	NR	NR	Successful aging involves engaging with others; coping with changes; and maintaining physical, mental and financial health
Ebrahimi 2013 [49] **(Sweden)**	22 frail older adults (65+) with diverse ratings of self-perceived health, purposefully selected from a sample who were included in a quantitative study after seeking emergency treatment in a hospital	Qualitative interviews	Content analysis	Influences on subjective experience of health	Can you describe a day/situation, where you experience health? What gives you a feeling of poor health? Please tell me more about your experiences, thoughts, and emotions / your everyday life.	Eriksson's definition of health (endurable suffering) was used as guiding framework	To feel assured and capable was the main theme, which consisted of five subthemes: managing the unpredictable body, reinforcing a positive outlook, remaining in familiar surroundings, managing everyday life, and having a sense of belonging and connection to the whole.
Everingham 2010 [50] **(Australia)**	33 members (50+) of seniors' groups, purposively selected and via snowball sampling	10 semi-structured interviews and 5 group interviews	Thematic coding	The meaning of aging well	What does aging well mean to you? What are the main issues that should be addressed to improve the lives of seniors in this community?	NR	Community perceptions of aging well are broadly consistent with the goals of national and international policy frameworks in focusing on 3 dimensions–health, social engagement, and security.
von Faber 2001 [51] **(the Netherlands)**	27 older adults (85+) participating in the longitudinal Leiden 85-plus Study, purposefully selected	In-depth interviews	NR	Perceptions about physical, social, and psychocognitive functioning and well-being	About the experience of growing old and being old, the perception of the concept of successful aging, and the role of health in successful aging	NR	Most elderly patients viewed success as a process of adaptation rather than a state of being. They recognized the various domains of successful ageing, but valued well-being and social functioning more than physical and psychocognitive functioning

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Table 1. (Continued)

Paper: Author year [ref] (country)	**Sample and recruitment**	**Data collection method**	**Data analysis approach / methodological orientation**	**Focus of study**	**(Example of) questions asked to participants**	**Theoretical perspectives / frameworks that guided development of questions, codes or interpretation of findings**	**Conclusion**
Fisher 1992 [52] **(US)**	19 older adults (62+) recruited at a Senior Activity center	Open ended interviews	NR	Understandings of successful aging and life satisfaction	What successful aging and life satisfaction meant to them, what was necessary for each, and what prevented each.	NR	There were some overlaps in understandings of successful aging and life satisfaction, but there was one key difference. Respondents described life satisfaction in terms of past expectations and present circumstances, while successful aging was more oriented to strategies for coping in later life and maintaining a positive outlook
Fisher 1995 [32] **(US)**	40 older adults (61+), randomly selected from employees of a foster grandparent program	Open ended survey questions	Content analysis	Understandings of successful aging and life satisfaction	What successful aging and life satisfaction meant to them, what was necessary for each, and whether these concepts were relevant to their own aging experience.	Erikson's concept of 'generativity' and Maslow's self-actualization hierarchy were used to interpret parts of the findings	Successful aging and life satisfaction are two different, yet related dimensions of subjective well-being. Understandings of successful aging involved attitudinal or coping orientations nearly twice as often as those for life satisfaction. Life satisfaction appeared to represent basic needs, whereas successful aging corresponded more closely to higher order needs such as self-understanding, helping others, and feeling like one has made a difference.
From 2007 [53] **(Sweden)**	19 older people (70+) dependent on community care, purposefully selected by a professional care needs assessor	Two interviews, 2–3 weeks apart	Content analysis	Views about health and well-being	What health, ill-health, well-being and ill-being meant to them	NR	The opportunity to feel healthy was dependent both on the older peoples' own ability to adjust or compensate, and on how the caregivers, relatives and friends in their environment could compensate for the obstacles the older people faced due to their disabilities.

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Table 1. (Continued)

Paper: Author year [ref] (country)	**Sample and recruitment**	**Data collection method**	**Data analysis approach / methodological orientation**	**Focus of study**	**(Example of) questions asked to participants**	**Theoretical perspectives / frameworks that guided development of questions, codes or interpretation of findings**	**Conclusion**
Fry 2000[54] **(Canada)**	37 older adults (58+), subsample of households participating in a community-based study	In-depth interviews following a open-ended survey	Content analysis	Considerations, priorities and concerns regarding QoL	What individual domains are the most important to your QoL? What specific concerns do you have about the QoL of your life?	NR	The majority of respondents has clear demands for autonomy, control and independence in making decisions, including the decision to terminate life.
Gabriel 2004 [55] **(United Kingdom)**	80 older adults (65+) living at home, purposively selected from respondents to a quantitative survey (The Quality of Life Survey)	In-depth interviews using semi-biographical interview techniques, repeated with half of the sample 1 year later if changes were reported	Thematic coding	Perspectives on QoL	What they thought of when they heard the words 'QoL', to describe their QoL, what gave their lives quality and what took it away, how it could be improved and what would make it worse.	NR	The main QoL themes that emerged were: having good social relationships, help and support; living in a home and neighbourhood that is perceived to give pleasure, feels safe, is neighbourly and has access to local facilities and services including transport; engaging in hobbies and leisure activities (solo) as well as maintaining social activities and retaining a role in society; having a positive psychological outlook and acceptance of circumstances which cannot be changed; having good health and mobility; and having enough money to meet basic needs, to participate in society, to enjoy life and to retain one's independence and control over life.
Gilbert 2012 [56] **(US)**	10 older adults (80+) living in an urban area, purposefully sampled, known by researchers	Semi structured interviews	Phenomenological approach	Perceptions of facilitators and barriers to healthy ageing	What do you do to stay healthy? What are the factors that help you remain active? What are the barriers to remaining active?	Dorthea Orem's Self Care Nursing Theory	Three themes were identified as facilitators to healthy ageing: taking care of self, meaningful activity; and positive attitude. Barriers to healthy ageing identified were: giving up or giving in; environmental limitations; and the ageing process.

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Grewal 2006 [57] **(United Kingdom)**	40 older adults (65+) living in private households, purposefully selected from a respondents to a general population survey	In-depth interviews	Thematic approach	Perceptions about QoL	What was important to them, what they enjoyed, got pleasure from, or valued in their lives. And, what is it about (factor) that is important to you, how does it make a positive contribution to your live?	Results were interpreted using work from Hyde, Higgs and colleagues that distinguishes attributes of QoL from the influences upon it; and Sen's functioning and capability approach	Initial discussions tended to concentrate upon factors influencing QoL including activities, relationships, health, wealth and surroundings. Further probing and analysis suggested five conceptual attributes: attachment, role, enjoyment, security and control. The data also suggested that QoL was limited by the loss of *ability* to pursue these attributes.
Hendry 2004 [58] **(United Kingdom)**	10 older adults (70+) recruited via day centres	Semi-structured interviews	Interpretative phenomenological analysis	Understandings of QoL	Questions focusing on five themes (physical health, psychological well-being, social relationships, environment and choice and control) and any aspects of QoL not covered yet	NR	Older people's understandings of quality of life are not readily measurable and should be viewed in terms of phenomenological experience: 1) when offered to give a general picture of QoL, people do not segment their lives into component parts; 2) participants often compared their own experiences to those of others (contextual experience); 3) participants did not share the experience of a linear effect of aspects of aspects on QoL 4) perceived QoL varies on an ongoing daily basis and participants choose which aspect of QoL to make public.

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Hinck 2004 [59] **(US)**	19 older adults (85+) living alone in their own home in a rural area, selected via purposive and network sampling techniques	In-depth interviews, at least 3 per participant	Interpretative phenomenology	Life experiences	Talk about what is meaningful to you. Tell me what yesterday was like	NR	Remaining at home is a strong value of even the oldest-old people. Although they might be managing day to day, their ability to continue safely at home might be tenuous and could easily be upset by illness or injury. Participants were creative in changing their environment and everyday practices and patterns to be able to complete most desired activities.
Hörder 2013 [60] **(Sweden)**	24 community- dwelling older adults (77+) recruited from a health promotion intervention	Open interviews	Content analysis	Perspectives on successful ageing	Tell me what successful ageing means to you	NR	Successful ageing can be seen as a preserved self-respect through ability to keep fear of frailty at a distance. This embraced the content of four categories: "having sufficient bodily resources for security and opportunities", "structures that promote security and opportunities", "feeling valuable in relation to the outside world", and "choosing gratitude instead of worries."
Kalfoss 2010 [61] **(Norway)**	20 older adults (60+) living in the community, selected via senior organisations or nurses when acutely hospitalized or attending ambulatory care	Focus group interviews	Thematic content analysis	Issues of importance to QoL	Think about what the phrase QoL brings to mind. What issues contribute positively or negatively to your QoL?	After analysis, themes were compared with Lawton's conceptualisation of QoL	Many valued aspects of human existence were found to affect QoL, and results lend empirica support to many of the themes appearing under Lawton's four sectors.

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Paper: Author year [ref] (country)	**Sample and recruitment**	**Data collection method**	**Data analysis approach / methodological orientation**	**Focus of study**	**(Example of) questions asked to participants**	**Theoretical perspectives / frameworks that guided development of questions, codes or interpretation of findings**	**Conclusion**
King 2012 [62] **(US)**	62 community- dwelling older adults with late-life disability, recruited from a senior care program (On Lok Lifeways)	Semi-structured interviews	Grounded theory (constant comparative analysis)	Factors that contribute to QoL	About participants' daily lives, including positive and negative aspects and descriptions of daily activities	NR	Participants described a range of factors in four domains (physical, psychological, social, spiritual) that contributed to their QoL. Dignity and a sense of control were central factors that had the strongest effect on QoL by allowing participants to build autonomy and self-worth.
Laditka 2009 [63] **(US)**	396 older adults from ethnically diverse groups living in the community, recruited within The Healthy Brain Project via a research network	Focus groups interviews	Constant comparative method	Views about ageing well, in the context of cognitive health	Please tell us about someone who you think is ageing well.	NR	There were notable race/ethnicity differences in perceptions of aging well. To promote cognitive health among diverse populations, communication strategies should focus on shared perceptions of aging well, such as living to an advanced age with intact cognitive function, having a positive attitude, and being mobile.
Levasseur 2009 [64] **(Canada)**	18 community-dwelling adults (60+), theoretically sampled based on disability level and QoL evaluation in a quantitative study	Two face-to-face semi-structured interviews (one week apart)	Phenomenological method	Perceptions and lived experiences about QoL in regards to personal factors, social participation and environment	In your own words, tell me what QoL means to you? What had the most positive/ negative effect on QoL? How do everyday activities influence your QoL?	Themes were inspired by a disability and functionings model and Dijkers' conceptualisation of QoL	These results point up the importance of considering perceptions about personal factors, social participation and environmental factors in older adults' QOL.
Llobet 2011 [65] **(Spain)**	26 older adults (75+) selected from a home health care service database, representative in age and gender	Face-to-face interviews with 4 open-ended questions	Content analysis, grouped into categories	Elements composing QoL	How do you define QoL? What are reasons for your QoL rating? What are aspects related to satisfaction with life?	Results are explained with Role Theory and Engagement Theory	Main reasons for a good perception of QoL were health, family and social relationships, and the ability to adapt.

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Lorenc 2012 [66] **(United Kingdom)**	37 older volunteers (61+) from community voluntary organisations, during a 'participant engagement event'	Focus groups	Content analysis	Perceptions and experiences of well-being (and decision making regarding complementary and alternative medicine)	Perceived meaning of well- being, changes in well-being since the group last met, and factors influencing well- being	Content analysis was partly informed by existing literature	"Keeping going" is important for older people. Five themes emerged: physical well-being, impact on activity, emotional issues, community and health services, and keeping positive.
Lysack 2002 [67] **(US)**	23 Caucasian and Afro-American community-dwelling women (85+) as exemplars of ageing well, identified via like-aged community peers	In-depth ethnographic interviews	Constant comparative method	Personal meanings of ageing and well- being	Questions to identify what growing older was like and what it meant to participants.	Interviews were analysed through the combined theoretical perspective of symbolic interactionism and continuity theory	Personal competence in the "feminine sphere" is key to understanding older women's healthbeliefs and behaviours in late life. Findings also point to the importance of occupational competence as a predictor of well-being in late life.
Milte 2014 [68] **(Australia)**	21 older adults (64+) attending outpatient day rehabilitation services (incl therapy gym and hydrotherapy sessions)	Semi-structured focus groups (including ranking exercise)	Mixed methods; for qualitative part structured content analysis was used with thematic coding procedures	Perceptions of QoL	Tell me about what QoL means to you? / Why did you rank this item as most/least important?	Existing QoL instruments used (ASCOT, OPQoL) for ranking exercise, on which the group discussion was based	Older adults value both health and social domains as important to their overall QoL.
Moore 2006 [69] **(Canada)**	11 older adults (65+) living in their own homes, lodges and senior complexes, recruited via a written invitation by colleagues of the authors	Narrative inquiry via in- depth interviews	Phenomenological reflection	Experience of meaning and purpose in life	As you reflect back over your life, what are meaningful, important experiences for you?	NR	It is in continuing to have a rich and satisfying life, even if it meant struggling a bit that seemed to contribute to a sense of meaning and purpose in life for the participants in this study.
Murphy 2009 [70] **(Ireland)**	122 older people with 6 types and different onset of disability, living in the community, purposeful selected	Interviews	Informed by grounded theory	Determinants of QoL	NR	Data collection was complemented by findings from international literature	We identified QoL factors that were important to older people with a disability, and these were consistent across groups, regardless of type of disability. 'Living well' was conceptualized as the core category.

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Nilsson 1996 [71] **(Sweden)**	87 older adults (75+) without severe somatic or psychiatric disorders, living in their own homes, participating in a multidisciplinary longitudinal study (Kungsholmen Project)	Structured interviews with standardized and open questions	Content analysis	Characteristics of QoL	What does QoL mean to you?	The Finnish sociologist Erik Allardt's definition of QoL was chosen as the conceptual framework for the study	The concept of QoL has many dimensions. A definition like Allardt's is too static and does not cover all aspects of the elderly's QoL. To sum up the characteristics of the QoL in old age, it can be stated that the emphasis is not on material things and the elderly's own persons but on contentment and a peaceful life, independence and health as a resource for this personal integrity in terms of moral qualities, and a caring attitude.
Nosraty 2015 [72] **(Finland)**	45 community- dwelling older adults (90+), invitation sent to every fifth woman and man born in 1921–22, living in the city	Life-story interviews	Thematic analysis with an inductive approach	The meaning and content of good and successful aging	What do you think constitutes a good old age? What do you need in order to experience a good old age? What things are associated with it? And what do you think a good old age is?"	NR	Good health is important, but morein the sense ofbeing pain-free than of being disease-free. Socialand cognitive aspects seem to be more important than physical health. The important things for our nonagenarian respondents were to continue living independently, preferably in their own homes, and to have a quick and easy death rather than being institutionalized.
Prieto-Flores 2010 [73] **(Spain)**	24 older adults (64+), purposively selected at public day care centers and public seniors' centers	Semi-structured interviews	Grounded theory	Connections between the subjective experience of health and other significant Qol domains	Around perceptions of aging, health, QoL, and health and social care	NR	Four major categories were identified: (a) adaptation to the limits of health in aging; (b) subjective health and QoL in aging: seeking a balance; (c) the experience of place in centers for older people; and (d) a central category, health and family interrelated dimensions of QoL in old age.

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Puts 2007 [74] **(the Netherlands)**	25 older frail and non-frail community-dwelling adults (65+), theoretically sampled based on 8 frailty markers from the Longitudinal Aging Study Amsterdam	Semi-structured interviews	Grounded theory	Meaning of QoL	E.g. What is the first thing that you think about when you hear the term QoL? What is important for your own QoL, and why?	Topic guide was based on a literature study on QoL	Five themes emerged: (physical) health, psychological well- being, social contacts, activities, and home and neighborhood
Reichstadt 2010 [75] **(US)**	22 community-dwelling adults (60+), purposively selected at retirement communities, a low- income senior housing complex, and a continued learning center	Qualitative interviews	The method of 'Coding Consensus, Co-occurrence, and Comparison' (Grounded theory)	Perspectives on successful ageing	E.g. How would you define successful aging? What is important to aging successfully? What are your suggestions on how to age well?	NR	Two primary themes were identified as key to successful aging– i.e., self-acceptance/ self-contentment (with sub-themes of realistic self-appraisal, a review of one's life, and focusing on the present) and engagement with life/ self-growth (with sub- themes of novel pursuits, giving to others, social interactions, and positive attitude). A balance between these two constructs appeared critical.
Richard 2005 [76] **(Canada)**	72 older adults (55+) living in an urban environment, recruited from purposefully selected seniors' groups and community organisations serving older adults	8 focus groups	Descriptive analysis	Factors affecting QoL	On factors related to or affecting QoL, measures to improve QoL and the role governments can play in the QoL of older adults	The ecological model of McLeroy et al. was chosen as an organising framework for categorisation of factors	A broad range of issues were discussed. The most salient themes were health and independence, financial security, social integration, health care services, housing, accessibility of community services, and decision-making power.

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Romo 2013 [77] **(US)**	56 community- dwelling older adults (55+) with late-life disability from different race/ethnic groups, recruited from a senior care program (On Lok Lifeways)	Semi-structured interviews	Grounded theory (constant comparative analysis)	Meaning of successful ageing	What comes to mind when hearing the term 'succesful ageing'? What does it mean to be old? Do you feel you've aged successfully? Do you feel old?	NR	An overarching theme was that aging results in *Living in a New Reality*, with two subthemes: *Acknowledging the New Reality* and *Rejecting the New Reality*. Participants achieved successful ageing by using adaptation and coping strategies to align their perception of successful ageing with their experiences. Themes were common across race/ethnic groups but certain strategies were more prominent among different groups.
De la Rue 2003 [31] **(Australia)**	5 rural older (65+) widowed women, voluntarily recruited based on a homogenous sampling strategy	Repeated in- depth interviewing based on a life history research approach	Thematic analysis	(Influence of the geographical location on) the meaning of health and well-being	Tell me about your life here on this property	Social constructionism and socio-environmental theory of gerontology provided the philosophical boundaries to the central research question	The informants' health and well-being were profoundly influenced by the geographical location of living on the land
Thomas 1989 [34] **(UK)**	20 older men (70+) residing in England, purposively selected (to match an Indian sample) from organisations serving the elderly (50 participants interviewed; analysis based on 20 participants);	In-depth open ended interviews	Hermeneutical approach	Life satisfaction / subjective well- being	About themselves, their past and their present situation (things they enjoy and dread, attitudes toward pain, pleasurable experiences, etc.)	NR	The samples (Indian and English) differ in overarching themes and their level of life satisfaction. The dominant theme for the English sample is dread of incapacitation, of becoming useless and dependent. The term that best describes these men is *stoic acceptance*, if not resignation.

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Tollen 2008 [78] **(Sweden)**	22 older adults (65+) with disabilities, purposefully selected from persons who applied for (but not yet started) day care rehabilitation	Qualitative interviews	Phenomenography	Everyday life experiences	'I would like you to tell me about your everyday life, what you do and how you experience your situation'.	NR	Disengagement in activities and social contacts resulted in feelings of resignation and dejection for some participants, while others delegated tasks as a satisfactory alternative. Participants also described how activities and social contacts continued, albeit in different ways, and being active and socializing gave feelings of pleasure and a sense of belonging. While receiving help was experienced as valuable, it also increased the fear of becoming dependent.

NR = not reported

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illnesses and frailty [59, 60, 67]. Some older adults are committed to improve their QoL by trying to influence their health with a positive attitude and an active lifestyle.

Health was described as important because it is the basis for many other QoL aspects: *"What mostly controls it is your personal health. That determines what you can do."* ([72], p.55). Good health appeared to facilitate the **ability** to carry out meaningful activities, to take care of yourself, to perform household tasks, to get out, communicate and participate. Murphy et al.
[70] noticed that especially as participant's physical functioning declined older adults started to redefine health in terms of abilities rather than absence of illness, e.g. *"Health is to a great extent being able to look after yourself"* ([49], p.292). Only when older adults were severely restricted in their 'going and doing' [42], they experienced poor health. Such experiences were connected with negative emotions of sadness, anxiety and sorrow [53].

Autonomy: Being able to manage on your own, retaining dignity and not feeling like a burden. Many older adults mention the desire to stay **independent** as long as possible:

"If I recover from this and can take care of myself, then I shall be satisfied. It's important not to have to trouble others, and to be able to carry out the duties I can" ([35], p.1116).

Participants say that being independent enables them to experience a sense of freedom and to enjoy life, by being able to socialise, to go outdoors and to do what you want. As Bryant et al. [42] noticed, respondents spoke with pride or pleasure of their independence, saying for example 'we can take care of ourselves' and by giving examples of everything they still do. Several participants indicated that the worst imaginable situations would be to become completely dependent on others or to end up in a nursing home.

Carrying out activities and daily routines independently contributes to a sense of **control**. For example, doing household task without help implies that older adults can decide themselves when and how it is done; i.e. to one's own specifications. Older adults emphasize that being dependent, or old, does not mean that one is unable to make decisions or express wishes:

"When it comes time for decisions concerning my health, my money, and how and where I want to live and die, I am fully in charge of myself and my family… Just because a man is getting old, and a bit slow does not mean that others can force their way into his life and tell him what's good for him." ([54], p.375).

When you are used to manage on your own without having to take into account another person's time and availability to help, it can be difficult to accept and acknowledge the need for help. Older adults do not want to be a **burden** to others. Although they value they value the assistance and support they receive, they often indicate that they are afraid to be(come) a burden to others. Some therefore withdraw from contact with friends and family *"You don't want to spoil theirs [enjoyment] and be a nuisance to them"* ([53], p.283) or even rather prefer the thought of passing away [35,42].

Authors of the included studies remarked that feelings of being a burden, guilt and embarrassment due to dependency affect older adults' self-image. This may be the reason why, rather than acknowledging to be dependent, many older adults characterised themselves as independent by emphasizing the things they can still do [77, 78]. Focusing on remaining abilities, personal care and appearance helps to retain **dignity**, and when care is needed: being helped and treated with respect for one's personal identity, wishes and values. From et al. [53] and Milte et al. [68] noticed that especially partners and relatives can help the older person to preserve an experience of dignity as they are well aware of their habits and are sensitive to their wishes: *"[My husband] always said 'I'm so lucky' because I was there to care for him and that gave him dignity and I feel that that dignity in our life is very important"* ([68], p.80).

Role and activity: Spending time doing activities that bring a sense of value, joy and involvement. Older adults living at home value the **control over their time**, i.e. the freedom to spend their time as they prefer: *"The most positive thing? I feel free … there's no rush … I want to take advantage of what I have to do before I can't do it anymore."*([64], p.e96). For one respondent, this freedom was even the definition of well-being: well-being means *"to get up and do as much as you want to when you want to"* ([42], p.933).

In almost all studies, respondents report that it is important for their wellbeing to **'keep busy'**, 'keep active' and 'have something to do' in order to avoid boredom and sink into apathy. For some however, particularly those with severe limitations, time passes by slowly: *"Yes, obviously, you are lying and thinking and sometimes dozing, even sleeping sometimes. There's nothing else to do. […] I do not know what to call it, do not have a name for it, but: deadly boring."* ([35], p.1120).

Respondents mentioned a broad range of **valuable activities** that brought joy or meaning to their life, including hobbies, mental and physical activities or more socially oriented activities, such as going out, travelling and participation in group activities. Indicative is the following quote: *"I love the theatre, I love the cinema … If it's just to go off for a day somewhere and have a meal in a pub … And I think that's very essential, it's just the simple pleasures of life really"* ([57], p.1897).

Older adults indicate that activities such as reading the newspaper, learning new things and keeping in touch with family and friends also help to **stay connected** with the world around them. They value feelings of belonging, participation and having a role in society, although they sometimes feel excluded: *"It's unfortunate that a lot of your family or other people feel that, once you're old, you don't know anything anymore and you're just kind of in the way."*([62], p.574)

Table 2. Domains and subthemes of quality of life.

Domains and subthemes	Description
Health perception	**Feeling healthy and not limited by your physical condition**
- [Physical conditions and symptoms]	- Not suffering from physical, mental and cognitive symptoms or disorders
- [Point of reference]	- Feeling healthy compared to prior health status or that of others
- [Health as an ability]	- Not being limited by your health
Autonomy	**Being able to manage on your own, retaining dignity and not feeling like a burden**
- [Independence]	- Being able to manage on your own and do what you want
- [Control]	- Being able to choose what you want
- [Burden]	- Not feeling like a burden to others
- [Dignity]	- Being able to retain dignity by focusing on things that one can do
Role and activity	**Spending time doing activities that bring a sense of value, joy and involvement**
- [Control over time]	- Having the freedom to organize your time
- [Keeping busy]	- Having something to stay occupied and keep you from feeling bored
- [Valuable activities]	- Doing activities that bring joy or meaning to life
- [Staying connected]	- Staying mentally active, up-to-date and in touch with the world around you
- [Helping others]	- Feeling able to contribute to society and making a difference
- [Achievements]	- Being proud on (and achieving a sense of identify from) current and former achievements
- [Self-worth]	- Feeling valuable and comfortable in your own skin
Relationships	**Having close relationships which makes you feel supported and enable you to mean something for others**
- [Close relationships]	- Having (and keeping) valued relationships
- [Family]	- Enjoying bond with partner and/or (grand)children
- [Experiencing support]	- Experiencing that people care for you and care about you
- [Love and affection]	- Experiencing a sense of belonging and intimacy, being loved and appreciated
- [Reciprocality]	- Having the possibility to help and support others
Attitude and adaptation	**Looking on the bright side of life**
- [Positive attitude]	- Being positive and making the best out of life
- [Acceptance]	- Being able to accept what you cannot influence
- [Changing standards/ expectations]	- Being able to put your situation into perspective (cognitively minimizing effects of deteriorations by lowering standards and comparing yourself favourably to others)
- [Changing behaviour]	- Being able to change habits, do things differently or with assistance from others/ aids
Emotional comfort	**Feeling at peace**
- [Calm vs worried/anxious]	- Having peace of mind (not feeling worried or anxious)
- [Happy vs sad/depressed]	- Being happy (not sad or depressed)
- [Loneliness]	- Not feeling lonely or isolated
- [Reminiscence]	- Not feeling troubled by past experiences
Spirituality	**Feeling attached to and experiencing faith and self-development from beliefs, rituals and inner reflection**
- [Being religious]	- Having religious beliefs, faith in God
- [Being spiritual]	- Being on a quest for meaning, self-development and awareness
- [Religious activities]	- Being involved in religious activities or a religious community
Home and neighbourhood	**Feeling secure at home and living in a pleasant and accessible neighbourhood**
- [Meaning of home]	- Having a home that provides privacy and comfort
- [Living at home]	- Living as long as possible in your own home
- [Safety]	- Feeling safe and secure at home and in the neighbourhood

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Table 2. (Continued)

Domains and subthemes	Description
- [Neighbourhood]	- Living in a pleasant neighbourhood with friendly neighbours
- [Accessibility]	- Being able to access and transport to important areas in the neighbourhood
Financial security	**Not feeling restricted by your financial situation**
- [Sufficient money]	- Having sufficient money to meet basic needs
- [Financial freedom]	- Having the financial freedom to enjoy life
- [Materials and conditions]	- Having material resources to feel comfortable and independent

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In order to feel valued and to gain a sense of purpose, older adults mentioned that they find it important to continue **helping others**, for example by volunteering, babysitting or caring for sick relatives. By doing so they feel they contribute to society and fulfil a role: *"I think the quality of life is being involved and having a part to play. I think if you lose your role in life then you start getting depressed, I think it is very important to be needed for whatever reason, and . . . kind of have self-worth or something and know that people think you are worthy."*([55],p.685]).

Current and former roles and **achievements** were often mentioned by older adults as something to be proud of. Specific examples for women were given in the study of Lysack & Seipke ([67],p.134): *"I feel as though I accomplish things when I can keep my own yard and keep my own house"*. For many respondents it feels important to continue the activities they have always done, as these are an important part of their identity.

Thus, older adults' **self-worth** is closely related to the activities they are able to do and achievements and roles in current and earlier life. The effect of limitations on one's self-image is for example described as follows: *"Yes, I think it's meaningless when I obviously can't be active in any way. . . You don't feel like a real human being in some ways, more like a vegetable or something"* ([35], p.1115). Respondents mention that it is important to have a positive picture of yourself, but that their self-worth is sometimes threatened by the feeling of being perceived as a nuisance in society.

Relationships: Having close relationships which makes you feel supported and enable you to mean something for others. Social contacts are seen as essential for QoL by older adults, they help to avoid loneliness. Especially **close relationships** are valued, as the quality of contact is most important: *"Togetherness is understanding and trusting someone else. Being able to talk to someone about things you wouldn't speak to others about and them doing the same."* ([53], p.282).

Many quotes show the importance of relations with **family** members; to provide help, support and love, and give joy and meaning in old age; e.g.: *"How can I put this, the* *older you get, the more you focus on your own family and your children. […]. Yes, you're there for each other."* ([74], p.269). Hörder et al [60] remarked that feeling loved by close relatives and caring about them can keep older adults from worrying and distract their attention. Especially partners and (grand)children are a source of joy and support, although the bond may also bring worries, conflict and sorrow. Fear of violence and abuse were only marginally reported [37, 54, 76].

Experiencing support (both practically and mentally) in personal relationships was a recurring theme, and older adults talk about how they appreciate being looked after by people that care about you, having someone you can call if you have any problems, and being encouraged in times of setbacks. Some older adults who lacked close relationships expressed the wish for support: "*I'd just want friendship*, *some compassion*, *understanding*, *empathy*." ([42], p.936). A bond with pets can provide support as well [40, 64].

Besides providing support, close relationships can be a source of **love, affection** and appreciation: *"Being in the company of my dear ones gives me a sense of belonging. It's nice to know that someone cares, and that they in turn can count on me when they need help or someone to talk to [. . .] Above all, I want to love and be loved."* ([36], p.43). Sexuality and intimacy were only briefly mentioned in the studies by Kalfoss [61] and Bryant et al. [42].

As shown in above quote, older adults want **reciprocal relationships** and mean something for others as well. Keeping relationships equitable may be especially important to maintain self-worth and diminish feelings of being a burden.

Attitude and adaptation: Looking on the bright side of life.

Older adults strongly believe that a **positive attitude** helps to have a good QoL. Older adults who adopted such a life philosophy described their motto as: stay positive, enjoy life, be happy with small things, make the best of life, and maintain your humour, optimism and curiosity. They emphasize one should not feel sorry for oneself, complain all the time or just sit down and do nothing.

In many ways, ageing relates to 'living in a new reality' [77]. In order to maintain a feeling of wellbeing, older adults state that it is essential to accept, adapt to and cope with life changes inherent to ageing, such as retirement, slowing of pace, declining health status (of partner) and loss of loved ones. Inability to adapt may result in feelings of sadness and despair. Some older adults even equate QoL with the ability to adapt:

"20 or 30 years ago, I might have listed some of the usual terms associated with the expression "good quality of life": good health, an adequate income, a reliable social network, good friends, and an enjoyable and encouraging job. Today, at the age of 86, my definition is different.
With a growing absence of those pleasures, I now see a good "quality of life" as the ability to adapt to an increasingly difficult situation without letting problems interfere with gratitude and joyfulness; to experience fine literature and music, and as far as one can manage, to be useful and encouraging towards other people. In other words, a good "quality of life" is the ability to endure

no matter what." ([36], p.43).

Older adults used several ways to adapt to difficult situations, including deliberate and unconscious processes. **Acceptance** is the strategy most often mentioned. Respondents recommend to make the best out of each situation and to take life as it comes by accepting what happens to them: *"You never do get over it but if you can accept it you can start taking the steps, you've got to . . . life's got to go on, hasn't it?"* ([55], p.683).

Some more unconscious coping processes that were identified include minimizing and denying limitations, laughing about difficulties, emphasizing abilities and skills that one had in the past, and **adjusting one's standard** of what is acceptable or important. A woman, who used to care a lot about looking representable and wearing panty hoses, now says, *"But it was so much trouble. [..] So I thought, what the heck, I'll just go bare legged. I don't care what people think about it"* ([59], p.787). Older adults put their situation into perspective by comparing their situation to others, or to what is normal or expected at their age. This could entail either 'upward comparisons' (e.g. inspired by the strength, will and optimism of others) or 'downward comparisons' (e.g. feeling grateful when considering your health better than that of your peers).

Older adults also adapt and maintain their QoL by **changing their behaviours** and habits. Some respondents, for example explain that they decreased their level and duration of activities in order to prevent fatigue or deterioration of their health: *"You have to take a rest and then you can do it again."* ([39], p.205). They also said to avoid risks and to be more cautious or attentive when carrying out tasks, and to seek more assistance from other persons, technology, aids and equipment. Some even anticipated to future limitations, such as moving to live near children or investing in a good physical or cognitive condition.

Emotional comfort: Feeling at peace.

Older adults indicated that they wish to feel **calm**, content, free from worries, in harmony with life and to have peace of mind. However, for some, these feelings are hampered by stress and worries about loved ones, low income, health and independence: *"The worries that drag around with you is like a weight you put in the trunk of your car that slows you down."* ([64], p.e95). Some older adults express severe levels of stress, and report to feel frightened, fear the future or have anxiety. This severely impacts their QoL.

Quite some respondents mentioned (often in relation with their positive attitude) to be **happy**, enthusiastic, embrace life, and appreciate or enjoy small things. Others report to feel sad, downcast, hopeless or even depressed. A participant in the study by Bernardo et al. ([37], p.77) said: *"Nothing has a positive impact on my quality of life. . . loneliness, sadness, that's what has damaged my quality of life the most."*

Loneliness, usually as a result of bereavement or moving into a new community, has a strong negative impact on older adults' QoL. Borglin et al. ([39], p.211) pointed out that the loss of a partner implies immense sorrow and a feeling of having lost an important part of oneself: *"The loss is indescribable, when you have been together for so many years, but that is why I say that I have lived my life, for the fact is that I'm not living any more, I only exist."* Losing connections with friends and family members is difficult as well: *"My best friends are all gone… and I feel that is one of the worst parts of getting old and surviving: you have to bear the pain of seeing them go."* ([42], p.935).

Lastly, the **reminiscence** of negative and positive past experiences can influence current feelings. Some memories are painful, e.g.: *"These memories, they never go away. No matter what pills you take, it doesn't take away the burden that I've been carrying right up till today"* ([72], p.53), whereas others bring joy, or feelings of accomplishment and gratefulness.

Spirituality: Feeling attached to and experiencing faith and self-development from beliefs, rituals and inner reflection.

Being religious or spiritual can support older adults in accepting disability or psychological distress, in coping with changes and being satisfied with life: *"It helps me to cope with happenings, incidents and so on, which would seem to be absolute tragedies to other people"* ([57], p.1895), and *"I just am so thankful for what the good Lord has given me."* ([42], p.937). Religion and spiritual beliefs shape their philosophy of life and can also relieve thoughts about death *"I am not afraid of dying […] I have had a good life and I look confidently forward to an even better after life."* ([39], p.205). Some older adults rely on their God and turn to him to help overcome problems. Faith gives them comfort, peace of mind and a sense of meaning and purpose in life, and makes them look forward to each day. Volunteering and taking part in **religious activities** and practices, such as going to church, were described as ways to stay socially active and involved.

However, there was large variation in the value older adults attributed to religion and faith. Some respondents commented that religion was not important at all: *"Well I haven't any faith in a personal God that's looking after you. If you know anything about astronomy you realise how stupid that is."* ([57], p.1895).

Spirituality is often mentioned as synonymous with religion. Yet, it may also encompass non-religious beliefs and rituals, such as meditation, self-development and turning attention to the inner life: *"I'm spiritually—not religious–I'm spiritually very calm with myself. I discovered things about myself in mid to later years that have been sitting there all the time."* ([75], p.570). For some older adults ageing means a certain kind of spiritual growth and becoming a wiser or better person.

Home and neighbourhood: Feeling secure at home and living in a pleasant and accessible neighbourhood.

The **meaning of home** for older adults often extends that of 'just a residence'; it brings about feelings of staying in a pleasant place with familiar and important objects and shared norms, history and values [49]. This is illustrated by a respondent: *"It's also important* *to have a safe place to live. It means a lot to have a flat that is adapted to your needs."* ([36], p.46). A home provides shelter, a place where one can feel safe and comfortable, and it is a private domain in which you are in control and can maintain your daily routines: *"my home is my castle"* ([39], p.212).

Many older adults strive to keep **living at home** or in the community for as long as possible and preferred adapting the home environment rather than moving; "*Well, the first condition is to stay fit enough to be able to live on your own. And to live at home; I'd much rather live here at home than in some institution*" ([72],p.54).

When becoming dependent on other people or services, the feeling of **safety** and privacy at home can be at stake. Older adults addressed how home adaptations and alarm systems increase their feelings of safety. Some were concerned about safety from crime in and around their home: *"After dark, we never go out. And we never answer the door unless we're expecting somebody; otherwise, our door remains closed"* ([74], p.271).

Having friendly neighbours and experiencing a sense of familiarity in your **neighbourhood** can enable a sense of security: *"I suppose it's security, ain't it—you've been in the area for a long time, you know where everything is, you know everybody locally—you feel more secure"* ([57], p.1894). Neighbours and social networks can provide help in everyday life and social contact. Furthermore, according to older adults QoL is enhanced by a pleasant environment which provides the opportunity to enjoy nature and do interesting activities.

However, some environmental barriers were mentioned that restricts older people from going out. These are for example poor weather and obstacles such as 'poorly maintained sidewalks, and street/traffic designs poorly adapted to older adults' [76]. **Accessibility** of the environment is a key to participation in community life [70]. According to Bowling et al. [40], lack of easy access to reliable, cheap and convenient public transport was mentioned as inhibiting social contacts and activities. Access to community services such as post offices and libraries was mentioned to be important as well.

Financial security: Not feeling restricted by your financial situation.

Good financial circumstances make life easier. Respondents mentioned their ability to meet basic needs, for example: *"It's having sufficient money… to do what you require, run your car, say, and pay your bills, and have the odd holiday… sufficient money not to have to worry about money"* ([41], p.838). Income affects people's capacity to pay for services such as home-help, physiotherapy and meals, or transport. It seemed that especially respondents who experienced financial difficulties mentioned finances as important for QoL.

Adequate finances are not only important to afford basic essentials and household bills, they also provide **freedom**: the possibility to afford outings, activities and extras. Older people can feel restricted by a lack of financial resources which hinders them to enjoy themselves and to participate in society (e.g. through holidays, going to the cinema, inviting friends for dinner, a train ride, luxuries) and to feel independent and secure (living comfortably and without worries). Respondents lacking sufficient money felt unable to enjoy life. *"There are so many things I would like to do that I can't afford and that is not fun"* ([39], p.212).

Next to having sufficient money, respondents mention how **material and (housing) conditions** help to feel comfortable and retain independence: *"I should buy myself one of those adjustable beds. And a chair that I could stand up (from) easily [. . .] Well, I'm talking millionaire, now, I would like a bath that you could get into easier, and all things that . . . I could be independent until . . . the rest of my days."* ([55], p.687).

Quality of life as a web of intertwined domains

The domains should not be interpreted as clearly demarcated and distinct units. Our findings rather imply that QoL can be understood as a dynamic web of domains, where each domain covers a swarm (or cluster) of strongly connected QoL aspects. During the analysis it became clear that the subthemes that describe the QoL domains sometimes overlap and are strongly connected with each other. Within quotations, these connections were visible by statements about how QoL aspects affect each other, for example: *"If you have a good mental outlook, you are probably going to be active and you're probably going to eat reasonably well"*([63],p.s34). Several connections and points of overlap between QoL aspects are exposed in the domain descriptions above, for example, the idea that being able to mean something for other people is important for your own QoL is part of the subtheme 'helping others' (domain Role and Activity) but also of the subtheme 'reciprocality' (domain Relationships). Moreover, it is strongly connected to the subthemes 'being a burden' (domain Autonomy) and 'self-worth' (domain Role and activity).

The domains are thus intertwined; they interact with each other and sometimes even partly fuse. However, a clear hierarchical picture of QoL domains, in which some domains can be identified as purely instrumental to other domains, was not found. Health was for example said to be needed for QoL aspects covered in other domains such as 'Role and activity' and 'Relationships', but certain activities and relationships also contribute to one's 'Health perception'.

All the interactive threads between the QoL aspects make the web dynamic: if something occurs in one of the domains it influences the rest of the web. This implies that the status of a domain for an individual is affected by the status of the other domains at that time.

Coverage of the QoL domains

Table 3 shows the 'coverage' of the domains in the individual studies. As such, it provides an overview of how extensive and consistently the QoL aspects that we categorised into these domains were mentioned across settings and subgroups of older adults. For example, the domains 'Autonomy', 'Role and occupation', 'Attitude and adaption', 'Health perception' and 'Relationships' were covered in almost all studies, suggesting that the QoL aspects categorised into theses domains are important across settings and groups. These QoL aspects were most detailed and extensively described in the studies and are therefore more prominent in our synthesis. QoL aspects categorised into the domains 'Spirituality' and 'Financial security' were less universal as they were less consistently covered across studies.

Discussion

Main findings

The purpose of this review was to synthesize the findings of qualitative studies that explored what QoL means to older adults living at home. The synthesis of 48 studies resulted in a categorization of QoL aspects into nine QoL domains: 'feeling healthy and not limited by your physical condition' [Health perception], 'being able to manage on your own, retaining dignity and not feeling like a burden' [Autonomy], 'spending time doing activities that bring a sense of value, joy and involvement' [Role and activity], 'having close relationships which makes you feel supported and enable you to mean something for others' [Relationships], 'looking on the bright side of life' [Attitude and adaptation], 'feeling at peace' [Emotional comfort], 'feeling attached to and experiencing faith and self-development from beliefs, rituals and inner reflection' [Spirituality], 'feeling secure at home and living in a pleasant and accessible neighbourhood' [Home and neighbourhood], and 'not feeling restricted by your financial situation' [Financial security]. While we distinguished these nine domains, the quotes from older adults often fitted into more than one domain and the quotes exposed numerous connections between domains. This implies that the concept of QoL can be understood as a dynamic web of domains meaning that the domains are strongly intertwined and are affected by the status of the other domains at that time.

Reflection on findings

Although it is often claimed by researchers [53,73] that little research has been done into the perspective of older adults on QoL to motivate the relevance of their empirical study, this review proves the opposite. There is a wealth of material available covering more than 25 years of research.

All authors of the primary studies used some sort of sub-classification of the themes they identified, which confirms that QoL is perceived as a multidimensional concept. The various ways in which primary authors labelled, classified and made sense of QoL aspects mentioned by older adults can be explained by our understanding of

QoL as a dynamic web of domains that strongly interact and partly overlap. However, we found that the content of the quotes from older adults themselves was very similar across the studies, showing common experiences and use of language to describe these experiences and the contribution to QoL. This means that under these diverse interpretations and conclusions there is something more universal in the meaning of QoL for older adults living at home in Western societies. Rather than using the more theoretical interpretations of QoL by the primary authors for our classification system we focused primarily on the quotes of older adults in order to grasp these universal experiences. Furthermore, our synthesis is a more comprehensive classification of QoL aspect compared to the QoL classifications in the primary studies.

In some of the included papers, domains such as 'Health perception', 'Home and neighbourhood', 'Spirituality' and 'Financial security' were characterized as instrumental to or as a resource for other QoL domains, because some older adults mention these themes merely as helping them to adjust and do the things they would like to do. In a similar vein, themes described under 'Attitude and adaptation' for example are often about strategies to improve QoL or maintain a good QoL. However, there are also fragments showing that these domains are important in itself or are influenced by aspects covered in the other domains, such as the activities that one participates in. It is therefore difficult to draw a line between domains that are more instrumental to QoL and domains that should be seen as ultimate QoL components, i.e. in cause and effect relation.

The domains 'Health perception', 'Autonomy', 'Role and activity', 'Attitude and adaption' and 'Relationships' were most extensively and universally covered across settings and participants. Although this suggest that these domains are most distinctive in characterising QoL, we think that the coverage of the domains not necessarily reflects the importance of these domains for QoL as conceived by older adults. For example, the domains 'Spirituality' and 'Financial security' were less extensively and consistently covered, but they seem very important for specific groups or individuals. Our list of domains should therefore be seen as a comprehensive framework of potentially important QoL aspects. The relative importance and meaning of the QoL domains depend on one's circumstances but also on personal preferences. This can be taken into account in a QoL measure by giving respondents the opportunity to indicate how their current situation relates to their needs in/wishes for certain domains as is for example done in the ASCOT [79,80].

The synthesis affirms that adaptation processes can result in a shift in perceived importance of domains, as well as in an altered understanding of what these domains mean to someone, also known as 'response shift' [79, 80]. For example, in case of declining health and independence, older adults seem to focus their description of health and independence on their remaining abilities. Rather than a strict or technical definition in terms of physical functioning (which may result in a characterisation of themselves

Table 3. Coverage of core domains by the included papers.

Domain	Number of studies	Paper references																							
		[35]	[33]	[36]	[37]	[38]	[39]	[40]	[41]	[42]	[43]	[44]	[45]	[46]	[47]	[48]	[49]	[50]	[51]	[32]	[52]	[53]	[54]	[55]	[56]
Health perception	41/48	◆◆	-	◆◆	◆	◆◆	◆◆	◆◆◆	◆◆	◆◆◆	◆	◆◆◆	◆◆	◆◆	◆◆	◆◆	◆◆	◆	◆◆	◆	-	◆◆	-	◆◆	◆◆
Autonomy	39/48	◆◆◆	◆◆◆	◆	-	◆◆◆	◆	◆◆◆	◆◆◆	◆◆◆	◆	-	-	◆◆	-	◆	◆◆	◆	◆	◆◆	◆	◆◆◆	◆◆◆	◆◆◆	-
Role and activity	41/48	◆◆◆	◆	◆◆◆	◆◆◆	◆◆◆	◆◆	◆◆◆	◆◆	◆◆◆	-	◆◆◆	◆	◆◆◆	◆◆	◆◆◆	◆◆◆	-	-	◆◆◆	-	◆	◆◆	◆◆◆	◆◆◆
Relationships	40/48	◆	◆◆	◆◆◆	◆◆◆	◆	◆◆◆	◆◆◆	◆◆	◆◆◆	◆	◆◆	◆◆	◆	◆◆	◆◆◆	◆◆	◆	◆◆	◆	◆	◆◆	-	◆◆◆	-
Attitude and adaptation	39/48	◆◆◆	◆	◆◆◆	-	-	◆◆◆	◆◆	◆◆	◆◆◆	-	◆◆◆	◆◆	◆◆	-	◆◆◆	◆◆	-	◆◆	◆◆◆	◆	◆◆◆	-	◆◆◆	◆◆
Emotional comfort	35/48	◆◆	-	◆	◆◆	-	◆◆◆	◆◆◆	-	◆◆	-	-		◆	-	◆	◆	-	◆◆◆	◆	◆	◆◆◆	◆◆	◆◆◆	-
Spirituality	22/48	-	-	-	◆	◆	◆◆	◆	-	◆	-	-	◆◆	-	-	◆◆	-	-	◆	-	-	-	-	-	-
Home and neighbourhood	31/48	◆	◆◆	◆◆	◆	◆◆◆	◆◆	◆◆◆	◆◆	-	◆	-	-	-	◆◆	-	◆◆◆	◆	◆	-	-	◆	◆	◆◆◆	◆◆
Financial security	25/48	-	-	-	◆◆	◆	◆◆	◆◆◆	◆◆	◆	◆◆	◆	-	-	-	◆◆	-	-	-	◆◆	-	◆	◆	◆◆◆	-

Domain	Number of studies	Paper references																							
		[57]	[58]	[59]	[60]	[61]	[62]	[63]	[64]	[65]	[66]	[67]	[68]	[69]	[70]	[71]	[72]	[73]	[74]	[75]	[76]	[77]	[31]	[34]	[78]
Health perception	41/48	◆◆	-	◆◆◆	◆◆	◆◆	◆◆	◆◆◆	◆	◆◆	◆	◆◆	◆◆	-	◆◆	◆	◆◆	◆	◆◆	-	◆	◆	◆◆	-	◆◆
Autonomy	39/48	◆◆	◆	◆	◆◆	◆	◆◆◆	◆◆	◆◆	◆◆	-	-	◆◆◆	◆	◆	◆	◆◆◆	◆	◆	-	◆◆	◆◆◆	-	◆	◆◆◆
Role and activity	41/48	◆◆◆	-	-	◆◆	◆◆◆	◆◆	◆◆◆	◆◆	◆◆	◆◆	◆◆◆	◆◆	◆◆◆	◆◆◆	◆	◆◆	◆	◆◆◆	◆◆◆	◆◆	-	◆◆	◆◆	◆◆◆
Relationships	40/48	◆◆◆	◆	◆◆	◆◆	◆◆◆	◆◆	-	◆◆◆	◆◆	-	-	◆	◆◆	◆◆	◆	◆◆◆	◆	◆◆	-	◆	◆	-	◆	-
Attitude and adaptation	39/48		◆	◆◆◆	◆◆◆	◆◆◆	◆◆◆	◆◆◆	◆◆◆	◆◆	◆	◆◆	◆◆	◆◆	◆◆◆	-	◆◆	◆◆	◆◆	◆◆	◆	◆◆◆	◆◆	◆	-
Emotional comfort	35/48	◆	◆◆	-	-	◆◆◆	◆◆	◆◆	◆◆◆	◆	◆◆	-	◆	◆◆	◆◆	◆	◆◆	◆	◆◆	◆	◆	-	◆◆	◆	◆◆◆
Spirituality	22/48	◆◆	-	-	◆	◆◆	◆◆	◆◆	◆	-	-	-	-	◆◆	-	-	◆◆	◆	◆◆	◆◆	◆◆	◆◆	◆	-	-
Home and neighbourhood	31/48	◆◆	◆	◆◆	-	◆◆	◆◆	-	◆◆	-	◆	-	◆◆	-	◆◆◆	-	◆◆	-	◆◆◆	-	◆◆	-	◆◆	-	◆◆
Financial security	25/48	◆◆	-	-	◆◆	◆◆	◆◆	-	◆◆	◆◆	◆	-	-	-	◆◆	◆	-	-	◆◆	-	◆◆	-	◆	-	-

- not mentioned

◆ Briefly mentioned

◆◆ Discussed

◆◆◆ Discussed extensively

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as 'unhealthy' or 'dependent' persons), they describe health in comparison with others of their age and in terms of ability to adapt and to carry out meaningful activities (which, in turn may shift from more difficult goals such as gardening to more easy tasks such as grooming and eating). So, both the importance an individual places on and understanding an individual has of each of the QoL domains are dynamic and change over the course of life.

Comparison with other studies

Stanley and Cheeck [18] only identified and reviewed four qualitative studies that investigated older adults' perspective on well-being, and the results of these studies were not synthesized whereas we synthesized findings of 47 studies. The activities and strategies listed in their review, however, are comparable to the domains identified in our synthesis.

In an earlier review by Brown et al. [19]), it was stated that QoL can theoretically encompass a wide ranging array of domains. The QoL components Brown et al identified from a mix of 45 surveys and qualitative studies among older adults were remarkably consistent to the themes identified in our review. Some of our subthemes like 'Home and neighbourhood' (a good home, safety, transport facilities and a pleasant environment) were mentioned in the review by Brown et al., but were allocated to other domains. Nothing was mentioned in the review by Brown et al. about 'Attitude and adaptation', while we found that older adults consider the ability to adapt to difficult circumstances essential for a good QoL.

Strengths and limitations

This study contributes to our understanding of QoL from the perception of older adults as it brings together the findings of 48 studies, covering views of more than 3,400 communitydwelling older adults from 11 Western countries. The synthesis therefore provides a more universal understanding of QoL than each study on its own. By recoding and synthesising the reported data rather than summing up a list of identified themes we aimed for a 'whole' greater than the sum of its parts.

The samples from the included studies were selected from very diverse populations, covering younger and older age groups, and active volunteers as well as vulnerable older adults. Although, we recognize that diversity of respondents/samples may influence how they characterize quality of life, our aim was to define the commonalities over these diverse respondents. Therefore, we analyzed the content of respondents' quotations, not their personal characteristics. Considering the fact that diverse populations were included, we are confident that our findings cover a wide range of views on what QoL means to older adults. Although some QoL domains prevailed more often in specific contexts, the identified domains were fairly consistent across the studies. This contributes to the credibility of the findings.

In our study and in the selection of articles, we did not use a fixed definition of QoL, but rather we employed a broader view on QoL. This is among others shown by our broad search which included search terms such as 'life satisfaction', 'successful aging' 'living well', 'wellbeing'. Our goal was to include all studies describing the perspective of older adults on quality of life, and not to engage in the theoretical discussion about existing definitions. An advantage of using such a broad approach is that the QoL domains presented here are all based on what is important to respondents themselves. A disadvantage might be that it is not clear how the domains identified in our study relate to other concepts of QoL, well-being or successful aging. Our broad search strategy is reflected in the fact that we only identified one additional paper from the reference list of one of the included studies. Thus, we are confident that we included virtually all relevant studies.

Because we found that similar QoL aspects were identified across the studies and because our coding scheme did not change much after analysing the first half of papers, we think that our QoL framework does not need to be revised considerably when new qualitative studies on this topic will be added. There may however be themes that older adults or interviewers are reluctant to address. One subtheme for example that is surrounded by an 'audible silence' [24] is intimacy and sexuality in old age. Although large parts of the texts in the papers concern relationships, hardly anything was reported about the importance of experiencing intimacy. It might be that this is a theme not considered important by older adults, but it also possible that they are reluctant to share their thoughts about this topic in interviews that focus on QoL [81].

To enhance the transparency about the origin and background of the QoL aspects identified in our synthesis we provided a table showing which QoL domains were covered in which papers (Table 3) and a table showing the 'signature features' [21] of the included studies, such as the sampling strategy, the focus of the study and the methodological orientation and theoretical frameworks used. Individual interviews as well as focus groups were included. The variety in signature features supports the conclusion that are findings are not influenced by one specific methodological orientation or theoretical framework.

However, there are limitations to condensing such a wealth of material. Sandelowski et al.'s question 'Can you sum up a poem?' ([21], p.366) very well reflects the challenge of synthesising qualitative studies. A synthesis undeniably leads to a selection of material which in itself already is the result of a process of condensing and interpretation of primary raw data done by the authors of the studies. We therefore refer readers to the individual papers if they are interested in more detailed discussions and interpretations of the identified domains. Tables 2 and 3 can serve as a guide for identifying relevant studies. Opponents of synthesising qualitative studies remark that the loss of explanatory context is a cause for concern as qualitative findings are often specific to a particular context, time and group of participants [21, 23]. We attempted to preserve some context by providing summaries and signature features of each study in Table 2.

A second caution concerns our own perspective and professional and personal backgrounds. Our classification of QoL domains as resulting from the synthesis is influenced by our own values, background and experiences, just like the various classification systems as constructed by the primary authors of the included studies. Our research is mainly health-oriented and less socially oriented, which likely shaped our interpretation of the experience of QoL by older adults living at home. Yet, the possible effect of our personal backgrounds is reduced by the variation of the authors and the thoroughness of the peer review process in all phases of the study.

Finally, we did not perform a formal quality appraisal of the included studies. Researchers vary in their opinion on the use of quality appraisal of qualitative studies in a synthesis [20, 21, 23, 24, 26, 28, 82–84]. Apart from the diverse opinions concerning what a 'good' qualitative study is, there is no consensus about the most appropriate role of such an appraisal. For example, Atkins et al. [23] experienced that appraising studies became an exercise in judging the quality of the written report rather than the research procedure itself. Campbell et al. [24], therefore, argued that only studies with fatal flaws should be excluded. Based on a subjective overall evaluation going from our personal experience with doing and reporting qualitative studies, we did not consider any one of the included studies as fatally flawed so did not see a reason to exclude one of them from the synthesis. Furthermore, because papers with mainly short descriptions and explanations of the data offer in general few insights, in several studies it was found that poorer quality qualitative studies contribute only minimally to a synthesis, adding weight to the better studies [23, 24, 26]. We found in our study as well that the studies that provided the most conceptually rich descriptions and comprehensive quotations of QoL aspects (as indicated in Table 3) automatically contributed most to our synthesis. Finally, assessment of quality is much more important when themes of the included studies are used. Since we did not use the codes used by researchers of the included studies, but defined a set of themes and codes ourselves that we applied to the data extracted from the included studies, we considered it unnecessary to assess the quality of the included studies.

Implications for care practice, measurement of QoL and further research

Stanley and Cheek's [18] conclusion that the older person's subjective perspective on wellbeing is lacking in the literature, does not hold anymore given the fair amount of studies that we have identified. Our review provides a guide to researchers by providing an extensive overview of individual qualitative studies providing a complete overview of QoL domains and subthemes and references to more specific sources.

Our findings show that autonomy and living at home are valued by older adults, which is in line with current ageing in place policies. Because the QoL web is dynamic and consists of intertwined domains, such policies likely affect other QoL domains and may result in negative consequences as well, for example in loneliness and safety. With more and more older adults ageing at home there will be an inevitable increased need for care services and support. Care and support for older adults living at home should be aimed at improving or maintaining QoL, foremost on the QoL domains that they value themselves. Perhaps the most important practical implication of this review is that a broad definition of QoL should be targeted, encompassing various interrelated domains. The identified domains can provide direction to care services and support, and consequences on all domains should be considered when developing personal care plans. These domains can be used in personal conversations about how older adults' QoL could be improved and to personalize their care. Because the QoL web is dynamic such plans should be updated and discussed regularly. Furthermore, although it can be discussed to what extent care services and support are responsible for all identified QoL domains in this synthesis, the domains should be considered as outcomes or important side effects in improvement processes, evaluation, monitoring or benchmarking of care services and support for older adults living at home.

The findings of our study may also be used by researchers developing new QoL measures for older adults. Currently, not all of the identified domains are sufficiently covered in existing QoL measurement instruments for older adults. Many available instruments focus on *health* related QoL and include physical and psychological dimensions [15, 16, 85, 86], especially the preference-based measures developed for use in economic evaluations [14, 17]. And preference-based measures adopting a broader perspective on QoL do not include a health dimension [87, 88]. Although these measures may be suitable for specific purposes, our findings suggest that from the point of view of older adults important domains are missing. Further research on the operationalisation and measurement of QoL domains least frequently covered (Autonomy, Role and activity, Attitude and adaptation, Spirituality, Home and neighbourhood, and Financial security) is recommended in order to increase the face validity of QoL instruments for older adults. Development of measurement instruments based on a broad definition of QoL in line with older adults' perspective may help guide care services to direct their policies at what is important for older adults.

Nonetheless, several findings from this review indicate that incorporating older adults' perspective in the measurement of QoL can be challenging. Especially the dynamic character of QoL and shifting reference points and concept definitions over time by older adults, suggest that it may be problematic to use generic, static instruments. Adaptive, flexible ways of measurement are probably more in line with the characterisation of QoL found in this review. We also recommend to carefully align the choice or development of instrument to the goals and setting of measurement.

Furthermore, the interrelatedness of domains and absence of strict boundaries between domains mean that for older adults, any classification of QoL domains may feel artificial. As Hendry & McVittie [58] put it: *"people do not segment their lives into component parts"*.

Conclusions

We identified nine QoL domains from 48 qualitative studies among different groups of older adults. Older adults value feeling healthy and not limited by their physical condition, being able to manage on their own, retaining dignity and not feeling like a burden, spending time doing activities that bring a sense of value, joy and involvement, having close relationships which makes them feel supported and enable them to mean something for others, looking on the bright side of life, feeling at peace, feeling attached to and experiencing faith and self-development from beliefs, rituals and inner reflection, feeling secure at home and living in a pleasant and accessible neighbourhood and not feeling restricted by their financial situation. Which domains apply in a specific situation needs to be decided by service providers and care professionals themselves, preferably by turning on specific domains using flexible measurement instruments. However, it is important that service providers and care professionals realize that the QoL domains are strongly intertwined meaning that changes in one domain likely affect other QoL domains.

Author Contributions

Conceptualization: Karen M. van Leeuwen, Miriam S. van Loon, Fenna A. van Nes, Judith E. Bosmans, Guy A. M. Widdershoven, Raymond W. J. G. Ostelo.

Data curation: Karen M. van Leeuwen, Miriam S. van Loon, Johannes C. F. Ket.

Formal analysis: Karen M. van Leeuwen, Miriam S. van Loon, Guy A. M. Widdershoven.

Funding acquisition: Karen M. van Leeuwen, Judith E. Bosmans, Henrica C. W. de Vet, Guy A. M. Widdershoven, Raymond W. J. G. Ostelo.

Investigation: Karen M. van Leeuwen, Miriam S. van Loon, Guy A. M. Widdershoven.

Methodology: Karen M. van Leeuwen, Miriam S. van Loon, Fenna A. van Nes, Judith E. Bosmans, Henrica C. W. de Vet, Johannes C. F. Ket, Guy A. M. Widdershoven, Raymond W. J.G. Ostelo.

Project administration: Karen M. van Leeuwen, Guy A. M. Widdershoven, Raymond W. J.G. Ostelo.

Writing – original draft: Karen M. van Leeuwen, Miriam S. van Loon.

Writing – review & editing: Karen M. van Leeuwen, Miriam S. van Loon, Fenna A. van Nes, Judith E. Bosmans, Henrica C. W. de Vet, Johannes C. F. Ket, Guy A. M. Widdershoven, Raymond W. J. G. Ostelo.

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S1 File. Search strategies per database

Search strategy for PubMed (28 November 2018)

[Mesh] = Medical subject headings

[tiab] = words in title OR abstract

Search	Query	Items founc
#5	(#1 AND #2 AND #3 AND #4)	**573**
#4	(("Qualitative Research"[Mesh] OR "Focus Groups"[Mesh] OR qualitative research*[tiab] OR qualitative method*[tiab] OR qualitative approach*[tiab] OR focus group*[tiab] OR (("Interview" [Publication Type] OR "Interviews as Topic"[Mesh] OR interview*[tiab]) AND (“semi-structured”[tiab] OR semistructured[tiab] OR unstructured[tiab] OR structured[tiab] OR informal*[tiab] OR “in-depth”[tiab] OR indepth[tiab] OR guide[tiab] OR guides[tiab] OR qualitative[tiab]))))	**17484**
#3	("Narration"[Mesh] OR perspective*[tiab] OR opinion*[tiab] OR perception*[tiab] OR experienc*[tiab] OR view[tiab] OR views[tiab] OR definition*[tiab] OR attribute*[tiab] OR component*[tiab] OR domain*[tiab] OR contribut*[tiab] OR importan*[tiab] OR meaning*[tiab] OR understand*[tiab] OR concept*[tiab] OR narrati*[tiab])	**692873**
#2	("Quality of Life"[Mesh] OR "Happiness"[Mesh] OR "Personal Satisfaction"[Mesh] OR life qualit*[tiab] OR "quality of life"[tiab] OR qol[tiab] OR happiness*[tiab] OR life satisf*[tiab] OR well being[tiab] OR wellbeing[tiab] OR ageing well[tiab] OR aging well[tiab] OR successful aging[tiab] OR successful ageing[tiab])	**36700**
#1	("Aged"[Mesh] OR elder*[tiab] OR older adult*[tiab] OR older people*[tiab] OR senior[tiab] OR seniors[tiab] OR oldest old[tiab] OR nonagenari*[tiab] OR octogenari*[tiab] OR centenari*[tiab] OR older person*[tiab])	**299023**

Search strategy for Ebsco/PsycInfo (28 November 2018)

DE = descriptors, keywords

TI = words in title

AB = words in abstract

#	Query	Limiters/Expanders	Results
S19	S10 AND S12 AND S13 AND S18		**5,57**
S18	S5 OR S7 OR S15 OR S17		**294,11**
S17	S9 AND S16		**151,64**
S16	S6 OR S8 OR S14		**428,05**
S15		Limiters - Methodology: -Focus Group, QUALITATIVE STUDY	**207,82**
S14		Limiters - Methodology: INTERVIEW	**239,61**
S13	S3 OR S4		**177,15**
S12	S1 OR S2 OR S11		**546,75**
S11	DE "Aging" OR DE "Aging in Place" OR DE "Physiological Aging"		**74,03**
S10	TI (perspective* OR opinion* OR perception* OR experienc* OR view OR views OR definition* OR attribute* OR component* OR domain* OR contribut* OR importan* OR meaning* OR understand* OR concept* OR narrati*) OR AB (perspective* OR opinion* OR perception* OR experienc* OR view OR views OR definition* OR attribute* OR component* OR domain* OR contribut* OR importan* OR meaning* OR understand* OR concept* OR narrati*)		**2,342,03**
S9	TI (“semi-structured” OR semistructured OR unstructured OR structured OR informal* OR “in-depth” OR indepth OR guide OR guides OR qualitative) OR AB (“semi-structured” OR semistructured OR unstructured OR structured OR informal* OR “in-depth” OR indepth OR guide OR guides OR qualitative)		**351,61**
S8	TI (interview*) OR AB (interview*)		**299,42**
S7	TI (“qualitative research*” OR “qualitative method*” OR “qualitative approach*” OR “focus group*”) OR AB (“qualitative research*” OR “qualitative method*” OR “qualitative approach*” OR “focus group*”)		**58,81**
S6	DE "Interviews"		**8,16**
S5	DE "Qualitative Research"		**20,93**
S4	TI (“life qualit*” OR "quality of life" OR qol OR happiness* OR “life satisf*” OR “well being” OR wellbeing OR “ageing well” OR “aging well” OR “successful aging” OR “successful ageing”) OR AB (“life qualit*” OR "quality of life" OR qol OR happiness* OR “life satisf*” OR “well being” OR		**151,13**

	wellbeing OR “ageing well” OR “aging well” OR “successful aging” OR “successful ageing”)		
S3	((DE "Quality of Life") OR (DE "Happiness")) OR (DE "Satisfaction" OR DE "Life Satisfaction" OR DE "Marital Satisfaction" OR DE "Need Satisfaction" OR DE "Role Satisfaction")		**80,06**
S2	TI (aged OR elder* OR “older adult*” OR “older people*” OR senior OR seniors OR “oldest old” OR nonagenari* OR octogenari* OR centenari* OR “older person*”) OR AB (aged OR elder* OR “older adult*” OR “older people*” OR senior OR seniors OR “oldest old” OR nonagenari* OR octogenari* OR centenari* OR “older person*”)		**350,9**
S1		Limiters - Age Groups: Aged (65 yrs & older)	**299,33**

13 **Search strategy for Ebsco/CINAHL (28 November 2018)**

14 MH = mapped heading, keywords

15 + = mapped headings with explosion

16 TI = words in title

17 AB = words in abstract

#	Query	Limiters/Expanders	Results
S11	S3 AND S4 AND S9 AND S10		**4,44**
S10	S5 OR S8		**185,64**
S9	TI (perspective* OR opinion* OR perception* OR experienc* OR view OR views OR definition* OR attribute* OR component* OR domain* OR contribut* OR importan* OR meaning* OR understand* OR concept* OR narrati*) OR AB (perspective* OR opinion* OR perception* OR experienc* OR view OR views OR definition* OR attribute* OR component* OR domain* OR contribut* OR importan* OR meaning* OR understand* OR concept* OR narrati*)		**1,231,81**
S8	S6 AND S7		**91,62**
S7	TI (“semi-structured” OR semistructured OR unstructured OR structured OR informal* OR “in-depth” OR indepth OR guide OR guides OR qualitative) OR AB (“semi-structured” OR semistructured OR unstructured OR structured OR informal* OR “in-depth” OR indepth OR guide OR guides OR qualitative)		**227,98**
S6	(MH "Interviews+") OR (TI (interview*) OR AB (interview*))		**258,19**
S5	((MH "Qualitative Studies+") OR (MH "Focus Groups")) OR (TI (“qualitative research*” OR “qualitative method*” OR “qualitative approach*” OR “focus group*”) OR AB (“qualitative research*” OR “qualitative method*” OR “qualitative approach*” OR “focus group*”))		**150,41**
S4	((MH "Quality of Life+") OR (MH "Happiness") OR (MH "Personal Satisfaction")) OR (TI (“life qualit*” OR "quality of life" OR qol OR happiness* OR “life satisf*” OR “well being” OR wellbeing OR “ageing well” OR “aging well” OR “successful aging” OR “successful ageing”) OR AB (“life qualit*” OR "quality of life" OR qol OR happiness* OR “life satisf*” OR “well being” OR		**183,36**

	wellbeing OR “ageing well” OR “aging well” OR “successful aging” OR “successful ageing”))		
S3	S1 OR S2		**689,47**
S2	((MH "Aged+") OR (MH "Aging+") OR (MM "Attitude to Aging")) OR (TI (aged OR elder* OR “older adult*” OR “older people*” OR senior OR seniors OR “oldest old” OR nonagenari* OR octogenari* OR centenari* OR “older person*”) OR AB (aged OR elder* OR “older adult*” OR “older people*” OR senior OR seniors OR “oldest old” OR nonagenari* OR octogenari* OR centenari* OR “older person*”))	Limiters - Age Groups: Aged: 65+ years, Aged, 80 and over	**689,47**
S1		Limiters - Age Groups: Aged: 65+ years, Aged, 80 and over	**689,47**

18

19

20

21

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	3+4
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	4
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	-
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	5
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	5+6
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	55-59
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	5+6
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	6+7
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and	n.a.

PRISMA 2009 Checklist

		simplifications made.	
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	See discussion p. 41-42
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	n.a.
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	7+8

Page 1 of 2

Section/topic	**#**	**Checklist item**	**Reported on page #**
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	n.a.
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	n.a.
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	9
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	9-20
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	See discussion p. 41-42
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Table 3+4, + quotations
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	21-35
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	See discussion p.

PRISMA 2009 Checklist

			41-42
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	n.a.
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	37-39, 42-44
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	40-42
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	42-44
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	Editorial system

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: **www.prisma-statement.org**.

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CHAPTER 4

How do care services contribute to quality of life?

Views and experiences of Dutch older adults living at home.

Van Loon, M.S., Van Leeuwen, K.M., Ostelo, R.W.J.G., Bosmans, J.E., Metselaar, S., Widdershoven, G.A.M.

Resubmitted after major revisions

Abstract

Evaluations of care services are often quite narrow, focusing on whether care receivers are satisfied with a certain service, or whether health is improved. This paper explores how various care services provided to older people living at home in the Netherlands affect their quality of life (QoL) in a broad sense, by focusing on their experiences of these services.

Semi-structured interviews were conducted with seventeen older adults (65+) living at home, and receiving at least one of three types of care services - medical services, social support services and support in daily living - in different regions of the Netherlands. A theoretical framework on QoL distinguishing nine domains of QoL, which was based on a literature review, guided both the interviews and the analysis. A content framework analysis was used.

For older persons living at home, the services impact a broad range of QoL domains. Although the influence of services on QoL was mostly positive, for instance by fostering autonomy and relationships or by providing older adults with activities increasing their self-worth, negative impact on QoL was reported if services are not adjusted to individual preferences or needs. Especially, this decreased the experience of autonomy. Our results also show that the impact of various services on QoL overlaps, as a service may influence several domains.

Services can impact a broad range of QoL domains. Moreover, the interaction between services and their impact on the various domains of QoL should be taken into account. Care services can influence QoL both in a positive way (for instance by fostering autonomy), and in a negative way (for instance by inducing feelings of dependency and not being able to make one's own choices). When evaluating these services these mixed impacts should be considered. Efforts should be made to maximize positive and minimize negative effects.

Introduction

The ageing population increasingly challenges health care systems in Western societies, since health care costs generally increase with age (Janssen et al., 2016, Jongen et al, 2015, Von Faber et al., 2001). It is found that providing care services at home is less expensive than institutional care (Turjamaa, 2013; Janssen et al., 2016), and that this is also in line with preferences of older adults themselves (Gregory et al., 2017; Turjamaa, 2013; Janssen et al., 2012; Lorenc, 2012). Against this background, the Social Care Act (WMO) was adopted in 2015 in The Netherlands (Maarse & Jeurissen, 2016). This law emphasizes the importance of providing good quality care services at home. The increased demand for care services at home instigates policy makers to make decisions about which and how services should be used; these decisions are especially relevant in the context of a just distribution of scarce resources and a growing population of older adults. This makes the evaluation of these services all the more important.

In the Netherlands, care services received by older adults at home are covered by the Social Support Act, and provision is the responsibility of local authorities (Rijksoverheid, 2021). Medical care is covered by the Dutch Health Insurance Act. We include three types of care in this study; medical, social and services that support in daily living. The overall objective of care is 'to enhance self-sufficiency and prolong independent living as long as possible (ageing at home)' (Verver et al., 2018). Of all people aged 75 and over, 92% live at home and almost 25% of these people use support and care (SCP, 2019). In the Netherlands, 44% of the health care budget is spent on older adults and this is expected to rise to 59% in 2040 (RIVM, 2020; Wouterse et al, 2016).

Currently, evaluations of these services are often quite narrow, focusing on whether care receivers are satisfied (Johansson et al., 2002; Suhonen et al., 2012), or whether health is improved (Willemstein et al., 2009). This does not provide a full picture of what clients themselves find important in terms of QoL. An overview of what clients themselves find important in terms of QoL in relation to these care services is lacking. In order to evaluate these care services, it is important to identify what matters to older adults in terms of QoL. In turn, this helps in identifying what their care needs are.

Our aim is not to compare the outcomes of services but to understand individual experiences with care services and the way care needs of respondents are addressed. Addressing these care needs adequately can improve their QoL (Slade et al., 2004). Moreover, information on how older adults experience different aspects of QoL and how these different aspect are interconnected can help deciding what aspects of care could still be improved (Gregory et al., 2017). QoL has different definitions, thus it is important to have a clear definition. We use the Qol framework from a previous systematic review [blinded for review]. We chose this QoL framework because of the elaborate investigation of QoL domains. Since this framework was based on an extensive analysis of the literature, we expect that most relevant domains of QoL are included.

The aim of this paper is therefore to explore how care services provided to older people living at home in the Netherlands affect their QoL by focusing on their experiences of these services. Hence, the main question of this qualitative study is: What are the views and experiences of older adults living at home regarding the contribution of various care services to their QoL? To answer this question we have interviewed seventeen older adults receiving at least one of these services. We apply a theoretical QoL framework from a previous systematic review to understand relevant outcomes.

Methods

This qualitative study is based on in-depth interviews with older adults living at home. For the interviews, a topic list was used that was based on a theoretical framework of QoL domains. This framework was also used in the analysis, enabling the identification of the contribution of various care services to the various domains of QoL.

Concepts and theoretical framework

Quality of life

In order to get insight into the contribution of care services to QoL, we used a framework of QoL domains which was the outcome of a thematic synthesis of empirical studies on QoL in older adults (van Leeuwen et al., 2019). This framework consists of nine QoL domains; 1) autonomy 2) role and activity 3) health perception 4) relationships 5) attitude and adaptation 6) emotional comfort 7) spirituality 8) home and neighborhood 9) financial security. Table 1 presents these domains of QoL including the subdomains, and gives definition for each of them.

Domains and subdomains	Definitions
1. Autonomy	**Being able to manage on your own, retaining dignity and not feeling like a burden**
Independence	*- Being able to manage on your own and do what you want*
Burden	*- Not feeling like a burden to others*
Dignity	*- Being able to retain dignity by focusing on things that one can do*
Control	*- Being able to choose what you want*
2. Role and activity	**Spending time doing activities that bring a sense of value, joy and involvement**
Control over time	*- Having the freedom to organize your time*
Keeping busy	*- Having something to stay occupied and keep you from feeling bored*
Valuable activities	*- Doing activities that bring joy or meaning to life*
Staying connected	*- Staying mentally active, up-to-date and in touch with the world around you*
Helping others	*- Feeling able to contribute to society and making a difference*
Achievements	*- Being proud on (and achieving a sense of identity from) current and former achievements*
Self-worth	*- Feeling valuable and comfortable in your own skin*
3. Health perception	**Feeling healthy and not limited by your physical condition**
Physical conditions and symptoms	*- Not suffering from physical, mental and cognitive symptoms or disorders*
Point of reference	*- Feeling helathy compared to prior health status or that of others*
Health as an ability	*- Not being limited by your health*
4. Relationships	**Having close relationships which makes you feel supported and enable you to mean something for others**
Close relationships	*- Having (and keeping) valued relationships*
Family	*- Enjoying bond with partner and/or (grand)children*
Experiencing support	*- Experiencing that people care for you and care about you*
Love and affection	*- Experiencing a sense of belonging, being loved and appreciated*
Reciprocity	*- Having the possibility to help and support others*
5. Attitude and adaptation	**Looking on the bright side of life**
Positive attitude	*- Being positive and making the best out of life*
Acceptance	*- Being able to accept what you cannot influence*
Changing standards/ expectations	*- Being able to put your situation into perspective (cognitively minimizing effects of deteriorations by lowering standards and comparing yourself favourably to others)*
Changing behaviour	*- Being able to change habits, do things differently or with assistance from others/aids*

6. Emotional comfort	**Feeling at peace**
Calm vs worried/ anxious	- *Having peace of mind (not feeling worried or anxious)*
Happy vs sad/depressed	- *Being happy (not sad or depressed)*
Loneliness	- *Not feeling lonely or isolated*
Reminiscence	- *Not feeling troubled by past experiences*
7. Spirituality	**Feeling attached to and experiencing faith and self-development from beliefs, rituals and inner reflection**
Being religious	- *Having religious beliefs, faith in God*
Being spiritual	- *Being on a quest for meaning, self-development and awareness*
Religious activities	- *Being involved in religious activities or a religious community*
8. Home and neighbourhood	**Feeling secure at home and living in a pleasant and accessible neighbourhood**
Meaning of home	- *Having a home that provides privacy and comfort*
Living at home	- *Living as long as possible in your own home*
Safety	- *Feeling safe and secure at home and in the neighbourhood*
Neighbourhood	- *Living in a pleasant neighbourhood with friendly neighbours*
Accessibility	- *Being able to access and transport to important areas in the neighbourhood*
9. Financial security	**Not feeling restricted by your financial situation**
Sufficient money	- *Having sufficient money to meet basic needs*
Financial freedom	- *Having the financial freedom to enjoy life*
Materials and conditions	- *Having material resources to feel comfortable and independent*

Table 1: Quality of life domains (van Leeuwen et al., 2019)

Care services

Various care services can support older adults in living at home. In this study, we distinguish three types of care service commonly used by older adults living at home, because we expected differences in their perceived influence on QoL:(1) medical services, such as general practice care and physiotherapy, (2) social support services, such as adult community centers, and (3) services providing support in daily living, such as meals and transport. Medical services include services focusing on treatment, prevention and promotion of health, including medication, nursing care, allied health (physiotherapy, rehabilitation at home), hospital care (medical specialists), general practice medicine and mental health care. Social support services aim to support the social life of older people, such as adult community centers, social work, buddy or befriending systems, and leisure management. Support in activities of daily living includes domestic help, personal care (showering, getting dressed), meals, adaptation of the home, transport.

Sample and participants

This study included seventeen adults in the age group of 65 years and older living at home and who were able to participate in an interview and who received at least one of the three care services.. People living in an institution or having cognitive problems (to the extent that it would seriously hinder their participation in the interview) were excluded from participation. We used purposive sampling, aiming to capture a variety in backgrounds of respondents, specifically in the types of care services received. Other background variables in which we sought variation between respondents were region of residence and gender. Potentially eligible participants were approached through organizations providing care to older adults living in a rural area of the Netherlands (Limburg) and an urban environment (Amsterdam), or through their general practitionser. The general practitioner was not involved in the provision of the care services that were included in this study. During a visit to the general practitioner or care organization, potentially eligible participants received a letter describing the study and were asked whether they were willing to participate. Before the interviews, respondents received written information about the purpose and procedure of the study. The aim of the study was explained, that is: investigation of their experiences with care services and their quality of life, as well as what was expected of them (participating in an interview of approximately an hour, about their perspective on QoL and services). As described in Table 2, 17 participants were willing to participate, the youngest was 66 and the oldest 91. We stopped approaching new respondents when data saturation was reached; meaning that no additional information was obtained anymore in new interviews.

Data collection

This qualitative study combines a deductive and inductive approach. The QoL framework from a previous study served as a deductive element. Possible influences of care services were investigated in an inductive way. The first and second author conducted most of the interviews together in the homes of the respondents or in adult day care centers. The other interviews were conducted by the first author. Data collection took place between March 2016 – January 2017. The interviews lasted between 40 and 120 minutes. Interviews had the character of 'open [..] conversations' (Ebrahimi, 2013), loosely based on a topic guide including the nine QoL domains of the theoretical framework described above. Respondents were asked about the kind of services they received and how, in their perception, these services influenced their QoL. In an iterative process, after the first interviews and throughout the study, the topic list was adapted to incorporate the preliminary results of the interviews while remaining open to input of respondents. Data was recorded using a digital audio recorder and transcribed verbatim.

Data analysis

We used content framework analysis (Forman & Damschroder, 2007) to analyze how each of the services influenced older people's QoL. This is an example of thematic content analysis, focusing on presenting qualitative data descriptively (Anderson, 2007). The data were independently analysed by the first two authors, who both have experience with qualitative research. The transcriptions of the interviews were read several times in order to understand the overall perceptions of older adults about how their QoL is influenced by health care services. Each transcript was summarized and quotes about QoL and/or services were categorized using the QoL theoretical framework. A continuous discussion and peer debriefing between the authors during the different steps of data analysis and development of the codes and themes took place until consensus was reached. The analysis consisted of several steps: 1) transcription of the interviews (author1); 2) general exploration of the data (author1,2); 3) independently creating initial codes based on the QoL framework (author 1,2); 4) comparing initial codes and finding consensus about general themes; 5) describing the themes, using the framework, illustrating the themes with relevant quotes (author 1,2). Our analysis framework including codes and themes is available to the reader upon request.

Ethical considerations

Prior to the study, approval was given by the Research Ethics Committee of [*blinded for review]*. At the beginning of the interview, respondents were informed that taking part in this study was voluntary, that they could stop the interview at any time, that they were not obliged to answer all questions, that the content of the interview was confidential, and that reported data would be made unrecognizable.. Enough information was still obtained from these interviews to inform the analysis.

Findings

In total, seventeen older adults were included in this study. Nine respondents were living in a rural area of the Netherlands, and eight respondents were living in an urban environment. Table 2 describes the characteristics of the respondents included in the study.

Respondent (Gender)	Age	Living situation	Medical services	Social support services	Support in everyday life problems
R1 (F)	84	Alone, widower	Yes	No	Yes
R2 (M)	82	Alone, wife in nursing home	Yes	No	Yes
R3 (F)	80	Alone, widower	Yes	Yes	Yes
R4 (F)	84	Alone, widower	Yes	Yes	Yes
R5 (M)	70	married	Yes	Yes	Yes
R6 (M)	77	Alone, divorced	Yes	Yes	Yes
R7 (M)	79	Lives with R8	Yes	No	Yes
R8 (F)	81	Lives with R7	Yes	No	Yes
R9 (M)	72	Married	Yes	No	Yes
R10 (F)	66	Living together	Yes	Yes	Yes
R11 (F)	69	Alone, widow	Yes	Yes	Yes
R12 (F)	91	Alone, widow	Yes	No	Yes
R13 (M)	82	Relationship	Yes	No	Yes
R14 (F)	83	Alone, widow	Yes	No	Yes
R15 (F)	78	Alone, widow	Yes	Yes	Yes
R16 (F)	83	Alone, widow	Yes	Yes	Yes
R17 (F)	76	Married	Yes	Yes	Yes

Table 2: Characteristics of respondents

In the following we describe the experiences of the respondents of the influence of care services on their QoL according to the domains presented in Table 1. The number in parantheses refer to the domains as presented in Table 1. Table 3 summarizes the influence of the three care services on the 9 QoL domains, both positive or negative. X means no influence was expressed during the interview.

QoL Domain	Medical services	Social support service	Support in daily living
1. Autonomy	*+ Living at home, mobility* *- Lack of control*	*+ Choosing activities* *- Not being able to go out independently*	*+ Mobility, independent living* *- Being dependent on transport and food services*
2. Role and activity	*+ Staying occupied, self-worth*	*+ Staying occupied, enjoyment and pride in achieving tasks*	*+ Remaining active* *- Dependency on schedules of caregivers*
3. Health perception	*+ Improved functionality, reduced pain* *_ Side effects of treatments*	*X*	*X*
4. Relationships	*+ Personal relationship with care givers*	*+ Social contacts* *- Difficulties in communication*	*+ Personal relationships with professional caregivers and friends*
5. Attitude and adaptation	*+ Comparison to others who are worse off*	*X*	*+ Accomodation to and acceptance of changed circumstances*

Table 3: influence of care services on QoL domains

Medical services

Our results show that medical services influenced a range of QoL aspects according to older adults. Firstly, medical services supported the **autonomy (1)** of respondents, by enabling them to remain living at home, and be more mobile and independent. After surgery, R9 had been bedridden for three weeks, because of which his muscle strength diminished. Physiotherapy at home helped to get him out of bed again and perform activities on his own. Medical services also influenced autonomy in a negative way. Respondents felt they had to undergo medical care, without having a say in this. Again, R9 provides an example. When his mobility improved, he became bored of the exercises that were advised by his physiotherapist. He also was not pleased with the medication for his heart because it made him feel dizzy.

> *'From my cardiologist I always get this pile of pills. My arm broke twice because the pills made me dizzy. And then I took all the pills back to the pharmacy. And now I don't use anything and I feel much better.'*(R9)

By making his own decisions; changing the exercises and returning the medication, he was able to regain control.

Medical services also influenced the respondent's **role and activity (2)** in a positive way. Visits to and from caretakers filled the days of some of the respondents, kept them busy, or for some these visits were even the most important moment of a day. R11 for example appreciated the daily visit of the nurse, not only for nursing care assistance, but also for having coffee with her. He liked this most, although he knew this was not part of her work instructions:

> *'So I get up in the morning and they take care of me. Then I make a sandwich and have a cup of coffee. Together with the nurse. It's not allowed [laughing] but I do it anyway! Yeah, actually it is not allowed.'*

Furthermore, medical support also increased older adults' self-worth and sense of self; e.g. by timely changing catheters feelings of hygiene and appearance were improved.

Not surprisingly, medical services also support the **health perception (3)** of respondents, although they generally did not restore health. Many respondents suffered from one or more conditions within a wide range of medical problems; rheumatism, colon cancer, brain damage, paralysis, and different kinds of functional impairment. These medical problems can decrease older adults' ability to perform daily tasks. Respondents explained how medical services and/or medication support their health; although their conditions usually were of chronic nature, functionality could still be improved, or stabilized. The quote from R11 illustrates this:

> *'Well it doesn't help but it also doesn't make it worse. My condition remains basically the same, and that in itself is very important. That it does not deteriorate.'*

Nursing care can support health, for example by cleaning and dressing wounds. R4 received nursing care every day; the nurse dressed her wounds and also helped her to put on support stockings which reduces pain:

> *'Yes, that's good. The pain has been reduced. My legs used to hurt a lot, they were completely covered with wounds and I have been in the hospital for that'*

Medication and physiotherapy can help to reduce or take away pain. Yet, medication may also influence health in a negative way, for instance by causing side effects, as shown in the following quote of R10:

> *'I have nerve stimulation and quite severe medication against the neurological pain now; a daily dose of 3x5g of methadone. So now I am always tired, also because of the pain, you get tired [..] so they say. For me, being tired is the worst of it all'*

Many respondents reported to have built a personal **relationship (4)** with their caregiver, as they were seeing them for many years. Some respondents indicated having a relationship that goes beyond that of caregiver and care receiver. R7 and R8 for example had to say goodbye to their nurse after three years, which they deeply regretted. However, they arranged to still see her in the future,

> *'She said she'll come anyway. When the raspberries are ripe for the picking; she likes them. So I told her: come here to pick the raspberries, we are not able to eat them all anyway'.*

Meeting other people in the context of medical care also positively influenced **attitude and adaptation (5).** R14 believed many people in her physical therapy group are worse off than herself:

> '*Seeing those other people makes me realize I am not in such a bad shape myself. If I see them, I feel quite blessed'*

Respondents explained that having contact with their caregivers also positively influences their **emotional comfort (6).** For example, R2 indicated that his social network was diminishing; he therefore appreciated social contact with the nurses.

> *'At present I'm already happy with the nurse coming in the morning. And fortunately I get along quite well with them. And they all drink coffee here, they all want to have a coffee here. [..] Because I always have something; apple pie or cake or another pastry. Something I make myself. And I can always joke with them. [..] So that stirs things up around here a bit, you know.'* (R2)

Emotional comfort was not only influenced by contact with care providers, but also by engaging in activities with others in the context of the services provided. R13 and R14 for example, both attended physiotherapy in a group with other people. This had a positive influence on emotional comfort, by making them happy and reducing feelings of loneliness. It helped them establishing and maintaining valuable relationships:

> *'I have been doing that for at least 15 years already, with the same group, so you really get to know each other!'* (R14)

However, respondents also reported negative influences of meeting other people in the context of medical care on emotional comfort. As people grow older, many pass away, which increases feelings of sadness. As R13 explained:

> *'We started out as a group of nine and now three of us remain. That is painful. The rest of them have passed away.'*

The QoL domains **spirituality (7), home and neighborhood (8),** and **financial security (9)** were not explicitly discussed by older adults in relation to medical services.

Social support services

Social support services influenced **autonomy (1)** and their **role and activity (2)** in a positive way. Going to an adult day care center supported older adults' independence. Respondents also indicated that if activities corresponded to their wishes and if they were able to choose an activity they value and enjoy doing, control was fostered. This is illustrated by a quote from R10, who was happy to go to the day center because creative activities suited her and she was able to choose between various options:

> *'Because I am quite a creative person. I quite enjoy it. [..] I used to do all kinds of things; clay modelling and all kinds of things'.*

However, respondents also mentioned that visiting the daycare center limited their control, as they cannot leave the center on their own, and were dependent on the caregivers to go out.

Keeping busy was a recurrent theme; R11: *'otherwise you will not do anything at all during the day at home'*. Many respondents indicated that their main daily activity at home was watching television: *'At home I lie on the couch often. Watch some television and* *more of that. I am unable to read anymore'*. For some respondents, going to the day center was more than simply keeping busy, it provided them with a valuable and enjoyable way to spend their time. Several respondents experienced a sense of achievement by completing craftwork and being proud of the results. R 16 explained they are making Christmas cards: *'The cards are sold in the shop downstairs, and with the revenue other things are bought'*. However, not all activities connected to their personal interests.

Respondents explained that social support services enabled them to have **relationships (4)** and social contacts. Adult day care and community centers provided the opportunity for small talk with peers. R11 regarded the people she meets in the center as '*her family*'. R6 described that, despite the fact that he was very well able to be on his own, he enjoyed having social contacts at the center:

> '*At least I have some social contacts in this way.. I am able to entertain myself [..] I have been divorced for thirty four years, so being alone is normal for me. That is a way of life for me.'*

In some instances however, there were difficulties in contact or communication between people in an activity center, R17: '*it happens that someone crosses a border, if you have an argument, things can sort of come out in a certain way, I don't think that's appropriate*'. R17 herself liked to be a bit more on her own: *'I don't interfere with anyone! I sit in my own corner. I look around, I have my opinions, and I stay quiet.'*

Emotional comfort (6) was positively influenced by social support services. Being in the day care center may lift one's spirits as R6 explained:

> *'I like everything they do here [..] I'm fine with everything. I: what would happen if you could not come here anymore? R: well then.. what will I say.. then the world would collapse for me'*

Having social contacts on a regular basis also reduces feelings of loneliness. Every Wednesday, R3 goes to a 'living room', an initiative to bring older people together to reduce loneliness in her neighbourhood, which enabled her to socialize with other women: '*And gradually you get to know some people. Even people who live in the same apartment building.'*

The QoL domains **health perception (3)**; **attitude and adaptation (5)**; **spirituality (7)** and **home and neighborhood (8)** were not explicitly discussed by older adults in relation to social support services.

Support in daily living

Respondents indicated that services that provide support in daily living are crucial for remaining relatively independent in one's own home, and thus increase **autonomy (1)**. By adjusting the home, for instance by installing mobility aids such as a stair lift and providing devices such as visual aids or adjustments to the bathroom, daily living support services increased people's independence. A recurring subject was the mobility scooter that enabled respondents to go outside on their own and for example to buy their own groceries (R1, R3) '*Generally I go outside every day, getting some fresh air*' (R1). Inside the house, a walker enabled respondents to walk around. Yet, daily living support services also influenced respondents' autonomy negatively, as needing these services showed that they needed help and had little control over how things are done. Respondents for example mentioned having to wait for transport services. This is emphasized by R2, who disliked having to wait for the arrival of the transport service:

> '*When I order a minivan [at the transport service], I hope it will be in time. Sometimes they are way too early, sometimes they are way too late. And when you have to return back home it is exactly the same.*' (R2)

An aspect of autonomy is being able to eat what you want, whenever you want. This was affected both positively and negatively by services. Services providing meals enabled respondents to live at home. Yet, respondents often disliked the food they received from these services.

> '*I dislike deep frozen food. Deep frozen vegetables. What you get is all frozen. So now I try, now things are better again, to clean my own vegetables again. Sometimes it works, sometimes it doesn't.*' (R11)

Respondents explained that support in daily living services are relevant for the domain of **role and activity (2)**. R7 explained that he uses the wheelchair which he received from the services to remain active:

> '*With the wheelchair, I am able to rake leaves in the garden. That works quite well.*'

Daily living services supported people in organizing their time which contributes to their control over time. Some respondents mentioned that receiving support in taking care of personal hygiene, e.g. in taking showers made them feel more presentable, and thus more positive about themselves. Yet, **role and activity (2)** was also influenced negatively. Having different caretakers entering the home during the day influenced the control over time or schedule negatively, and respondents indicated to be dependent on the schedule of the caretakers.

Caregivers providing support with problems in everyday life influenced the domain of **relationships (4)**. Similar to medical services, having a personal relationship with caregivers providing support in daily living was valued. Transport services enabled older adults with decreased mobility to visit their friends and family and, thereby, maintain their relationships with them.

Daily living services supported older adults in changing their **attitude and adaptation (5)**, by helping older adults to change their habits and doing things differently with assistance from various devices such as a chair lift to go up and down the stairs, devices to pick up things from the ground, or devices that increase mobility (mobility scooter, walker). These services enabled people to adapt to their changed circumstances caused by their deteriorating health.

With respect to **home and neighborhood (8)**, safety was an important issue. Safety was related to trust in caregivers, which was a recurring topic in the stories of our respondents. Sometimes, caregivers had keys or a pass to respondents' front door so they could enter independently, while others felt not secure enough to provide their key. Another aspect of safety was a fear of falling and hurting yourself which was mentioned by some respondents. R6, for instance, had trouble with his balance and was afraid to fall in his home:

> *'Because if I start walking here during physiotherapy, when I am standing on the [treadmill] then I am holding the rail so tensely that my arms are starting to hurt'.*

An in-house alarm system relieved these feelings of anxiety and increased feelings of safety. All interviewed respondents received support in keeping their home clean and comfortable. Due to physical problems, performing the more demanding tasks like vacuuming was no longer possible for them. However, due to a recent cut in hours, many of the tasks respondents saw as important, were no longer part of the job. Cleaning windows for example, was often mentioned as a task that is not performed anymore.

Financial security (9) was supported through services supporting daily living, for example by assistance of social workers in case of financial problems. For some older people, management of their financial administration had become difficult and they worried about their situation. R2 for example was no longer able to take care of his administration, because he could not read and understand the bills he received, due to his lacking eyesight. R10 had financial problems, and worried about her situation because she was '*being hunted by a bailiff who wants to take possession of my income*'. She was visited once a week by a social worker to help her with her finances:

> *'It really helps me. Having someone to talk to if you have something on your mind. Someone who knows all about regulations. Because I don't know these things. Yeah, it helps a lot.'* (R10)

The financial security of some respondents was influenced negatively by the care service, as they had to pay themselves for expensive devices to support them, or had to contribute financially to received services. In other situations, respondents felt burdened by the costs of a new home that was more adapted to their changed physical circumstances:

> *'Because in this house, I have to pay 700 euro's per month. That startled me. Where I lived before, I lived almost for free. That was quite a big difference. I had to get used to that.'*

The QoL domains **health perception (3)**, **emotional comfort (6),** and **spirituality (7)** were not mentioned by respondents in relation to support in daily living services.

Discussion

This study provides insight into the experienced influence of medical services, social care services and services which support daily living on QoL of older adults living at home. For each type of service, we explored how these services impacted the nine QoL domains which we used as a theoretical framework: 1) autonomy; 2) role and activity; 3) health perception; 4) relationships; 5) attitude and adaptation; 6) emotional comfort;

7) spirituality; 8) home and neighborhood; 9) financial security (Van Leeuwen et al., 2019).

Our results show that, for older persons living at home, all three types of services have an effect on a broad range of QoL domains. When evaluating these services it is important to take these broad effects into account. Our results also show that the impact of the three services overlaps, as they can have similar effects on several domains. This implies that evaluating one service separately, using a limited set of outcome criteria, does not do justice to the experience of older people living at home and that a combination of services affects their QoL in an integral way.

We consider it probable that the effects of these services do not only overlap, but also reinforce each other. Therefore, we suggest adopting a broad QoL framework similar to the one used in this study to evaluate the outcomes of all services an older adult receives as a whole, taking into account their interaction. Several QoL questionnaires focusing on diverse aspects of QoL, such as the ASCOT (Netten et al., 2012) and the ICECAP-O (Coast et al., 2008), are available to evaluate the combined outcomes of services. Using these questionnaires to evaluate services in relation to one another may support decisions on distribution of services and goals of care better than evaluating services individually.

Our results show that medical services, social care services and, services that support daily living can influence QoL both positively and negatively. Although the influence of services on QoL was mostly positive, for instance by fostering autonomy and relationships, negative aspects are present if services are not adjusted to individual preferences or needs, especially in the realm of autonomy. Also, being dependent on others and not being able to make one's own choices diminishes respondents' QoL, for example when respondents had to wait for transport services. This is in line with other research on autonomy of older adults which shows that the organization of (home) care can restrict older people's ability to make autonomous decisions, whilst they have a 'strong inner drive to maintain autonomy in their own home' (Fjorside et al., 2016:285).

Previous research showed that older adults often tend not to complain explicitly about care they receive (Westerberg et al., 2017). However, our results suggest they do experience some negative aspects of care services, possibly influencing both QoL and quality of care. It is important to be sensitive to these negative experiences, especially considering the finding that older adults tend to remain silent about them, or only address them implicitly. Additionally, our results indicate it is important to make preferences and needs of a person (even more) central in the provision of care, as has been shown by previous studies as well (Clarke et al., 2013, Gallagher et al., 2008, Gregory et al., 2017). This is in line with recent developments such as value based health care that aim at improving quality of care by focusing on patients' preferences (Porter, 2010, Mohammed et al., 2016).

For older persons living at home, medical services do not primarily restore physical health, but provide support in maintaining an adequate level of functioning and helping them to cope with their health situation in various domains of life. Medical services contributed to many QoL domains other than health. This is in line with the concept of health recently put forward by Huber and colleagues, i.e. 'positive health', which states that health is "the ability to adapt and to self-manage in the face of social, physical and emotional challenges in life" (Huber et al., 2011).

Another important finding of our study is that older persons living at home are supported by care services in ways that go beyond the core tasks of professionals. Respondents valued for example having a cup of coffee and having a chat with caretakers who visit for medical purposes. However, these spillover effects of services are under pressure due to budget cuts (Janssen et al., 2016; Jongen et al., 2015; Maarse and Jeurissen, 2016). Specifying tasks for caretakers in such a narrow way that there is no room for flexibility to adjust to people's needs is expected to impact older adults' experiences with care negatively. Provision of social care support next to medical services for older adults allows for taking into account individual variation in wishes and needs, rather than provide a fixed and limited set of activities (Dunn, 2018). A move towards a person-centred approach can help to focus on older adults as individuals, enabling them to exercise their autonomy (Breitholtz et al., 2013). Shared decision-making, including patients and their family in care decisions, can also increase the quality of care (Cranley et al., 2020).

This study has some potential limitations. Several domains of QoL were not explicitly mentioned by respondents in relation to specific care services. For example, the QoL domain spirituality was not mentioned in relation to any of the care services, and home and neighborhood was only discussed in relation to support in daily living services. The fact that these domains were not explicitly mentioned does not mean they are not relevant for QoL. It does however indicate that these domains were not considered to be influenced by the services which are the focus of this paper.

Also,the results of this study have to be interpreted in the light of some methodological considerations. First, our analysis was based on a framework consisting of nine previously identified QoL domains (van Leeuwen et al., 2019). Consequently, we did not focus on identifying new concepts or domains regarding QoL, but rather on exploring the influence various care services have on these domains. Since this framework was based on an extensive analysis of the literature, we expect that most relevant domains of QoL are included in this framework. Secondly, although we included a heterogeneous population in this study and reached saturation, it is possible that our study sample is not fully representative for all older adults receiving care at home. Thirdly, in some cases, during the interviews, respondents reported being in pain, or being too tired to continue and in these situations it was decided to end the interview ahead of time. Enough information was still obtained from these interviews to inform the analysis. Fourthly, it should be noted that several informants were not living alone, as this could influence use of services (Slobbe et al., 2017) and feelings of dependency and autonomy. Their overall experience of autonomy could therefore be more positive compared to respondents who lived alone. Finally, the focus of this study was on the perspective of older adults themselves, whereas professional caregivers may have different views of how their services impact QoL. Also, informal caregivers were not included, although informal care may influence many aspects of QoL of older adults living at home. ~~We~~ recommend further research into the experiences of older adults living alone, and on experiences of formal and informal caregivers.

Conclusion

Since medical services, social care services and services that support daily living impact a broad range of QoL domains, evaluation should be based on an instrument which covers a wide set of QoL domains. Moreover, the interaction between services and their impact on the various domains of QoL should be taken into account. The three services can influence QoL both in a positive way (for instance by fostering autonomy), and in a negative way (for instance by inducing feelings of dependency and not being able to make one's own choices). When evaluating the services, we recommend to consider these positive and negative effects. Efforts should be made to maximize positive and minimize negative influences e.g. by having a conversation with the care receiver what aspects of QoL are important and how care could contribute. In doing so, making preferences and needs of a care receiver (even more) central in the provision of care is key. We recommend further research into the experiences of older adults living alone, and on experiences of formal and informal caregivers.

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Visited: May 3rd 2021

CHAPTER 5

Evalueren van kwaliteit van leven bij thuiswonende ouderen.

Overzicht en verantwoording van veertien relevante domeinen

Van Loon, M.S., Van Leeuwen, K.M., Ostelo, R.W.J.G., Widdershoven, G.A.M., Bosmans, J.E.

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Samenvatting

De groeiende groep thuiswonende ouderen in Nederland vraagt om een goede ondersteuning door inzet van de juiste diensten, zoals huishoudelijke hulp of dagbesteding. Het bepalen van belangrijke uitkomsten is daarin cruciaal en hiervoor zijn brede uitkomsten in termen van kwaliteit van leven (KvL) relevant, waarbij gekeken wordt naar de invloed van diensten op iemands mogelijkheden, of capabilities. In dit artikel worden de ontwikkeling en inhoud van de Adult Social Care Outcomes Toolkit (Nederlandstalige versie, ASCOT-NL) en de Extended Quality of Life Tool (EQLT) beschreven en toepassingsmogelijkheden in de evaluatie van zorg belicht. Beide instrumenten beogen effecten van zorg op KvL van thuiswonende ouderen te meten op meerdere relevante domeinen. De ASCOT-NL kent acht domeinen, de EQLT bevat deze acht domeinen en voegt daar zes domeinen aan toe, hetgeen resulteert in totaal veertien domeinen. De domeinen van de ASCOT-NL zijn gebaseerd op de doelen van sociale ondersteuning en zorg; de aanvullende domeinen van de EQLT zijn gebaseerd op empirisch onderzoek naar KvL vanuit het perspectief van thuiswonende ouderen en de manier waarop zorg kan bijdragen aan KvL.

Trefwoorden: ASCOT, thuiswonende ouderen, zorg, kwaliteit van leven, evaluatie-instrument

Summary

Assessing quality of life in older adults living at home: Overview and justification of fourteen relevant domains

An increasing group of older adults living at home in the Netherlands requires proper support through the use of services. Determining important outcomes is crucial in this respect. For this specific group, broad outcomes in terms of quality of life (QoL) are relevant, focusing on the influence of services on capabilities. This article describes the development and content of the ASCOT-NL (Adult Social Care Outcomes Toolkit, Dutch version) and the EQLT (Extended Quality of Life Tool), and highlights application possibilities in the evaluation of care. Both instruments aim to measure effects of care on QoL of elderly people living at home in multiple relevant domains. The ASCOT-NL has eight domains, the EQLT includes these eight domains and adds six domains, resulting in a total of fourteendomains. The domains of the ASCOT-NL are based on the goals of social support and care; the additional domains of the EQLT are based on empirical research on QoL from the perspective of older people living at home and how care can contribute to QoL.

Key words: care services, assessment tool, ASCOT

Inleiding

De zorg voor thuiswonende ouderen in Nederland is de afgelopen jaren drastisch veranderd. Er wordt in toenemende mate verwacht dat ouderen thuis blijven wonen, indien nodig ondersteund door diensten. [1,2,3] Ook groeit het aantal ouderen dat zorg ontvangt, mede door een langere levensverwachting en vergrijzing. [4] Het is belangrijk om eventuele toegevoegde waarde van diensten voor thuiswonende ouderen te kunnen meten.

In de huidige evaluatie van diensten wordt vooral gekeken naar de verbetering in gezondheid van cliënten en de EQ-5D is hiervoor een veel gebruikt meetinstrument. De EQ-5D is met name gericht op het meten van gezondheidseffecten.[5] Met vijf vragen worden vijf gezondheidgerelateerde dimensies gemeten: mobiliteit, zelfzorg, dagelijkse activiteiten, pijn en stemming. Voor veel ouderen is gezondheidsverbetering echter niet mogelijk. Andere aspecten van kwaliteit van leven (KvL), moeten daarom een grotere rol spelen als relevant doel van zorg. [6,7,8]

Vanuit deze optiek is het Nederlandse ASCOT project ontstaan. Wij willen een alternatief presenteren dat mogelijkerwijs interessant is voor het Nederlandse publiek. Het project gaat uit van het belang van een breed perspectief op KvL voor het evalueren van uitkomsten van zorg voor thuiswonende ouderen. Het vertrekpunt was de *Adult Social Care Outcomes Toolkit* (ASCOT) .[6] De ASCOT is één van de meetinstrumenten die aanbevolen wordt in het rapport “Verkenning effectmaat voor de care sector” als alternatief voor gezondheidgerelateerde KvL–meetinstrumenten, naast de ICECAP, OPUS en London Handicap Scale.[9] De ASCOT is ontwikkeld in het Verenigd Koninkrijk om de uitkomsten van *social care* te meten; dit zijn alle soorten zorg waar thuiswonende ouderen gebruik van kunnen maken.[6]

De *toolkit* bestaat uit verschillende instrumenten, waaronder een instrument waarin ouderen zelf KvL in verschillende domeinen kunnen rapporteren aan de hand van vier antwoordopties: de ASCOT SCT-4 (self-completion tool). Daarnaast bevat de *toolkit* onder andere een versie die door de mantelzorger kan worden ingevuld met drie antwoordoptie en een *easyread* versie. In dit artikel richten we ons op de SCT-4, hier kortweg aangeduid als ASCOT. De ASCOT bestaat uit acht domeinen; regie over het dagelijks leven; persoonlijke verzorging; eten en drinken; persoonlijke veiligheid; sociaal contact; tijdsbesteding; verzorgde woning en comfort; en waardigheid.[6] Deze domeinen worden gedekt door negen vragen.

Om het potentieel van dit instrument voor de Nederlands context te kunnen beoordelen en het instrument hiervoor bruikbaar te maken is de ASCOT vertaald in het Nederlands. Daarbij zijn de hiervoor geldende standaarden gehanteerd. [10] Dit heeft geleid tot eerste aanwijzingen voor de validiteit en betrouwbaarheid van de Nederlandstalige ASCOT-NL.[11] Tevens is onderzoek verricht naar mogelijke aanvullende domeinen van KvL die vanuit het perspectief van thuiswonende ouderen belangrijk zijn.[12] Dat onderzoek heeft geleid tot ontwikkeling van een instrument dat een uitbreiding vormt van de ASCOT-NL: de *Extended Quality of Life Tool* (EQLT).

Dit is een meer uitgebreide tool die ontwikkeld is voor de Nederlandse context en die gebruikt kan worden in verschillende situaties zoals het bespreken van KvL met ouderen in een persoonlijk gesprek.

In dit artikel beschrijven we beide tools en gaan we in op de vraag hoe ze binnen de Nederlandse context gebruikt zouden kunnen worden. Eerst beschrijven we de ASCOT-NL en de theoretische grondslag ervan, de *Capability Approach* (CA). Vervolgens beschrijven we de mogelijkheid om de ASCOT-NL in economische evaluaties te gebruiken. Daarnaast zullen we nader ingaan op de EQLT.

De ASCOT-NL

Achtergrond

De ASCOT is ontworpen om de KvL te meten van mensen die zorg ontvangen in de thuissituatie (*social care related quality of life*). De ASCOT kan toegepast worden bij een brede groep gebruikers in een groot aantal zorg- en ondersteuningssituaties.[13] Bij de identificatie en definiëring van de domeinen (zie tabel 1) is gekozen voor die domeinen die potentieel beïnvloed kunnen worden door ondersteunende zorgactiviteiten. Uit gesprekken met cliënten, experts en beleidsmakers, en focusgroepen en interviews met zorgontvangers in Engeland, blijkt dat de ASCOT daadwerkelijk de doelen van zorg omvat, met domeinen die zorgontvangers en beleidsmakers relevant achten.[13]

Capability Approach

De *Capability Approach* (CA) is een politiek-filosofische theorie waarin centraal staat dat mensen opties moeten hebben om te doen en te zijn wat ze waardevol achten.[14] Binnen de CA worden die opties, de mogelijkheden die iemand heeft, *capabilities* genoemd. Dit zijn de bouwstenen van KvL en volgens de CA is het ultieme doel van een rechtvaardige samenleving KvL, en dus *capabilities*, adequaat te ondersteunen. Dit verbreedt het perspectief van waardevolle uitkomsten in termen van KvL.

In de CA wordt een onderscheid gemaakt tussen *capabilities* – de mogelijkheden die iemand heeft, en *functionings* – de dingen die iemand doet. Wanneer iemand over een mogelijkheid beschikt, kan hij ervoor kiezen deze al dan niet te gebruiken. Iemand die toegang heeft tot voedsel, kan ervoor kiezen te eten maar kan ook bewust afzien van eten, bijvoorbeeld in geval van hongerstaking. Centraal staan zowel de beschikking hebben over mogelijkheden, als de vrijheid deze al dan niet te gebruiken. Dat betekent in ons voorbeeld dat het 'meten' of iemand honger heeft niet adequaat is om diens KvL te bepalen. Het meten van 'honger' focust alleen op de *gevolgen* en gaat voorbij aan de *reden* waarom iemand honger heeft. In termen van de CA: focussen op gevolgen gaat voorbij aan de mogelijkheden en de keuzes die een individu heeft. De CA als benadering om KvL van individuen te evalueren wordt inmiddels toegepast in de gezondheidseconomie.[7,15,16]

In een filosofisch onderzoek hebben we geanalyseerd in welke mate de CA daadwerkelijk geïncorporeerd is in de ASCOT, c.q. de ASCOT-NL.[17] Het onderzoek liet zien dat drie belangrijke uitgangspunten van de CA terugkomen in de ASCOT. In de ASCOT wordt ten eerste rekening gehouden met keuzevrijheid door de formulering van de antwoordoptie die voor elk domein het hoogste niveau van functioneren vertegenwoordigt, geformuleerd als 'zoveel als ik wil'. De andere drie antwoordopties geven een lager niveau van functioneren weer. Daarnaast is er een domein dat specifiek 'regie over het dagelijks leven' meet, dat eveneens keuzevrijheid in termen van de CA weerspiegelt.

Een tweede punt betreft adaptieve preferenties: het verlagen van verwachtingen bij verminderde mogelijkheden. De CA benadrukt het belang van ontplooiing van *capabilities* en van een kritische houding ten opzichte van de neiging die mensen kunnen hebben om wensen aan te passen aan beperkingen in de situatie. Dit komt in de ASCOT op twee manieren tot uitdrukking. Ten eerste wordt uitgegaan van een lijst van 'basisfuncties', die iedereen ten minste moet hebben.[18] Dat zijn functies die voor alle mensen in de samenleving relevant zijn. Ten tweede worden de preferenties van de algemene bevolking gebruikt voor de weging van de domeinen.[19] Dit betekent dat de bijdrage van de verschillende niveaus van de 'basisfuncties' aan KvL wordt vastgesteld door te bepalen hoe deze door de maatschappij worden gewaardeerd. Dit worden preferentiewaarden genoemd. Hierdoor speelt het aanpassen van wensen bij verminderde mogelijkheden door het individu geen rol bij het evalueren van uitkomsten met behulp van de ASCOT. Ten derde meet de ASCOT bredere uitkomsten dan alleen gezondheid door uit te gaan van acht KvL domeinen.

De ASCOT is geïnspireerd door de CA. We concluderen dat de CA een theoretische basis biedt voor de ASCOT, met een breed perspectief op KvL en dat de ASCOT geschikt is voor het evalueren van uitkomsten van zorgdiensten die andere aspecten van KvL beogen te beïnvloeden dan enkel gezondheid.

De ASCOT-NL

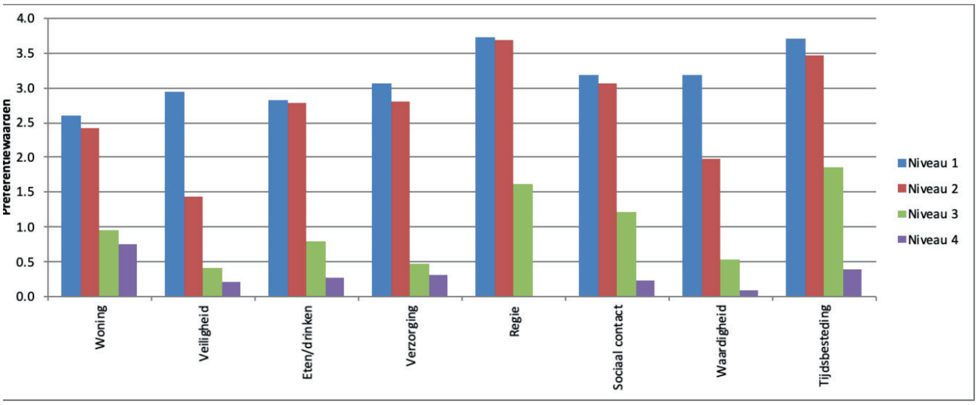
De ASCOT-NL is de vertaling van de Engelstalige ASCOT en bestaat dus ook uit acht domeinen. Per domein zijn er 4 antwoordopties, waarbij optie 1 telkens het beste niveau aangeeft en optie 4 het slechtste. Bijvoorbeeld: voor het domein "regie over het dagelijks leven", luidt de vraag: Welke van de volgende uitspraken beschrijft het best hoeveel controle u heeft over uw dagelijks leven? De antwoordopties zijn: 1) Ik heb zoveel controle over mijn dagelijks leven als ik wil; 2) Ik heb voldoende controle over mijn dagelijks leven; 3) Ik heb enige controle over mijn dagelijks leven, maar niet genoeg; 4) Ik heb geen controle over mijn dagelijks leven. Voor het domein waardigheid zijn (als enige) twee vragen opgenomen. De eerste vraag luidt: Welke van de volgende uitspraken beschrijft het best hoe het hebben van hulp uw zelfbeeld beïnvloedt? De antwoordopties zijn: 1) Het hebben van hulp heeft een positieve invloed op mijn zelfbeeld 2) Het hebben van hulp heeft geen invloed op mij zelfbeeld 3) Het hebben van hulp heeft soms een negatieve invloed op mijn zelfbeeld 4) Het hebben van hulp heeft een volstrekt negatieve invloed op mijn zelfbeeld. De tweede vraag luidt: Welke van de volgende uitspraken beschrijft het best in hoeverre u zich gerespecteerd voelt door de manier waarop u wordt geholpen en behandeld? De antwoord opties zijn: 1) Door de manier waarop ik word geholpen en behandeld voel ik me gerespecteerd 2) Door de manier waarop ik word geholpen en behandeld heeft geen invloed op hoe ik me voel 3) Door de manier waarop ik word geholpen en behandeld voel ik me soms niet gerespecteerd 4) Door de manier waarop ik word geholpen en behandeld voel ik me volstrekt niet gerespecteerd. De volledige ASCOT_NL is te vinden op https://www.pssru.ac.uk/ascot/translations/ en is vrij verkrijgbaar na registratie via https://www.pssru.ac.uk/ascot/licensing/.

Domein	Definitie
Regie over het dagelijks leven	De persoon kan kiezen wat zij wil doen en wanneer zij dit wil doen, heeft controle over het dagelijks leven en activiteiten
Persoonlijke verzorging	De persoon voelt zich zelf schoon en comfortabel en ziet er representatief uit, of op zijn best, is gekleed en gekapt op een manier die de eigen persoonlijke voorkeuren weerspiegelt
Eten en drinken	De persoon heeft het gevoel een voedzaam, gevarieerd en cultureel gepast dieet te hebben met genoeg eten en drinken waar hij/zij van geniet, op regelmatige en tijdige momenten.
Persoonlijke veiligheid	De persoon voelt zich veilig en zeker. Dit betekent dat de persoon vrij is van angst of en geen risico loopt op misbruik, vallen, of andere fysieke schade.
Sociaal contact	De persoon is blij met de sociale situatie. Met sociale situatie wordt hier bedoeld het onderhouden van betekenisvolle relaties met vrienden, familie en het gevoel hebben betrokken te zijn of del van een gemeenschap, indien dit gewenst wordt door de persoon.
Tijdsbesteding	De persoon kan zijn tijd besteden zoals de persoon zelf wil met verschillende, betekenisvolle activiteiten, zoals werk, vrijwilligerswerk, zorgen voor anderen of vrije tijdsactiviteiten.
Verzorgde woning en comfort	De persoon heeft het gevoel dat de huiselijke omgeving, inclusief alle kamers, schoon en comfortabel is.
Waardigheid	De negatieve en positieve psychologische impact van steun en zorg op het zelfrespect van de persoon.

Tabel 1 De ASCOT-NL domeinen en hun definities

Gebruik van de ASCOT-NL voor economische evaluaties

Om de ASCOT-NL te kunnen gebruiken in economische evaluaties werden Nederlandse preferentiewaarden ontwikkeld. Deze preferentiewaarden geven weer hoeveel de afname van kwaliteit van leven is wanneer iemand problemen ervaart in één van de kwaliteit van leven domeinen die opgenomen zijn in de ASCOT-NL.



Figuur 1 Nederlandse preferentiewaarden voor de ASCOT-domeinen. Hoe hoger de preferentiewaarde, hoe meer deze antwoordoptie bijdraagt aan de kwaliteit van leven van een persoon. De slechtste optie van het domein regie heeft de grootste negatieve impact op kwaliteit van leven en is daarom op 0 gesteld. De grootste bijdrage wordt geleverd door de beste opties van de domeinen Regie en Tijdsbesteding.

Uit het onderzoek blijkt dat de twee hoogste niveaus van functioneren voor het domein “Regie over het dagelijks leven” (hoogste twee antwoordopties ‘Ik kan mijn leven inrichten zoals ik wil’ en ‘Ik kan mijn leven voldoende zelf inrichten’) het vaakst gekozen werden als meest wenselijke optie in vergelijking met antwoordopties behorende bij de andere domeinen. De laagste niveaus van functioneren voor de domeinen “Waardigheid” (‘Door de manier waarop ik word geholpen en behandeld voel ik me volstrekt niet gerespecteerd’) en “Regie over het dagelijks leven” (‘Ik kan mijn leven niet zelf inrichten’) werden het vaakst gekozen als slechtste optie. Het feit dat deze opties van het domein “Regie over het dagelijks leven” het vaakst gekozen worden als slechtste en beste opties laat zien dat het domein “Regie over het dagelijks leven” het belangrijkste domein is in de ASCOT-NL.

Vervolgens zijn met behulp van multinomiale logit regressies de preferentiewaarden geschat, ofwel hoe groot de bijdrage van de verschillende antwoordopties per domein is aan de totale KvL. Hieruit blijkt dat het hoogste niveau van functioneren voor de domeinen “Regie over het dagelijks leven” en “Tijdsbesteding” de grootste bijdrage leveren (zie figuur 1).

Met behulp van deze preferentiewaarden kan een utiliteitsscore berekend worden die vervolgens gebruikt kan worden om voor kwaliteit van leven gecorrigeerde levensjaren (*Quality-Adjusted Life-Years*, QALYs) te berekenen waarbij KvL breder gedefinieerd is dan gezondheid alleen. Deze utiliteitsscore geeft de relatieve wenselijkheid van een KvL profiel weer. Voor de ASCOT-NL heeft deze utiliteitsscore een schaal die loopt van -0.277 tot 1.0. Deze utiliteitsscore is geankerd op 0 (dood) en 1.0 (perfecte KvL). Negatieve utiliteitsscores zijn ook mogelijk en impliceren dat het betreffende KvL profiel als slechter dan ‘dood’ wordt beschouwd. Met andere woorden, de kwaliteit van leven van de betreffende toestand is zo slecht, dat de dood geprefereerd wordt. Hiervoor moeten de preferentiewaarden eerst geankerd worden op de schaal van de utiliteitsscores. Dit is gebeurd met een zogenaamd 'time trade-off' experiment. Voor meer informatie over de preferentiewaarden verwijzen we lezers graag naar het artikel waarin de ontwikkeling van deze preferentiewaarden beschreven wordt.

De EQLT

Achtergrond

Binnen het Nederlandse ASCOT-project is onderzocht of naast de standaard ASCOT andere domeinen van KvL van belang zijn voor thuiswonende ouderen. Op basis van een systematische review van 48 studies naar KvL onder ouderen, (n=3400; 11 Westerse landen), zijn negen overkoepelende domeinen geïdentificeerd (Tabel 2).[12]

Domein	Definitie
Autonomie	*Ik kan mezelf redden, aangeven wat en hoe ik dingen wil, en heb niet het gevoel dat ik anderen tot last ben*
Gezondheid	*Ik voel me gezond*
Rol en Tijdsbesteding	*Ik besteed mijn tijd zoals ik wil, met activiteiten die ik leuk vind of die mij waardevol doen voelen*
Relaties	*Ik heb hechte contacten, waardoor ik mij gesteund voel, en ik kan ook iets voor anderen betekenen*
Attitude en aanpassingsvermogen	*Ik bekijk het leven van de zonnige kant*
Emotioneel comfort	*Ik ervaar innerlijke rust*
Spiritualiteit	*Mijn geloof/spiritualiteit helpt me om me dankbaar te voelen, groei te ervaren en om te gaan met moeilijke dingen*
Huis en omgeving	*Ik voel me thuis veilig en zeker, en woon in een prettige en toegankelijke buurt*
Financiële zekerheid	*Ik voel me niet beperkt door mijn financiële situatie*

Tabel 2 Kwaliteit van Leven domeinen (Van Leeuwen et al., 2019).

Uit het onderzoek blijkt dat vier van de negen domeinen worden gedekt door de ASCOT. Het domein 'Autonomie' bevat de ASCOT-domeinen 'Regie over het dagelijks leven' en 'Waardigheid'. Het domein 'Rol en Tijdsbesteding' bevat het ASCOT-domein 'Tijdsbesteding'. Het domein 'Relaties' komt overeen met het ASCOT-domein 'Sociaal contact'. Het domein 'Huis en omgeving' bevat het ASCOT-domein 'Verzorgde woning en comfort'.

De ASCOT domeinen 'Persoonlijke verzorging', 'Eten en drinken' en 'Persoonlijke veiligheid' komen niet expliciet terug in de systematische review. Het gaat hier om basale behoeften die eerder als voorwaarden voor dan als onderdelen van KvL beschouwd kunnen worden. De KvL-domeinen 'Gezondheid', 'Attitude en aanpassingsvermogen', 'Emotioneel comfort', 'Spiritualiteit' en 'Financiële zekerheid' komen niet aan de orde in de ASCOT. Dat geldt ook voor de woonomgeving als onderdeel van het domein 'Huis en omgeving'.

De bevindingen uit de review, de negen KvL domeinen, werden als kader gebruikt in interviews met thuiswonende ouderen die zorg ontvangen, om te onderzoeken welke invloed verschillende typen diensten (medisch, sociaal en ondersteuning in het dagelijks leven) kunnen hebben op hun KvL. Uit de interviews met ouderen bleek dat diensten ook bijdragen aan KvL op gebieden die buiten de oorspronkelijke ASCOT domeinen vallen. . De uitkomsten van de review en de interviews hebben geleid tot de formulering van zes aanvullende domeinen aan de ASCOT, resulterend in de EQLT.

De Extended Quality of Life Tool (EQLT)

De EQLT bestaat uit de 14 domeinen, met elk vier antwoordopties. Het betreft de acht domeinen uit ASCOT-NL aangevuld met zes additionele domeinen.Het verschil tussen de ASCOT-NL en de EQLT hangt samen met het feit dat bij de ontwikkeling van de ASCOT alleen aandacht is besteed aan expliciete doelen van zorg in het sociale domein. Daarmee biedt de ASCOT-NL geen ruimte voor evaluatie van bijdragen van diensten aan KvL die niet onder deze doelen vallen.

In een iteratieve consensusprocedure binnen het Nederlandse team, waarbij ook de ontwikkelaars van de ASCOT werden betrokken, is geanalyseerd welke domeinen vanuit het perspectief van thuiswonende ouderen zelf ontbreken in de ASCOT. Het resultaat van deze procedure was dat er zes domeinen zijn toegevoegd (tabel 3).

Domein	Definitie
Toegankelijkheid en (leeftijds)vriendelijkheid van de buurt	*De mate waarin iemand zijn/haar buurt als toegankelijk en (leeftijds)vriendelijk ervaart, met bijv. voldoende, veilige en goed bereikbare voorzieningen, voldoende en toegankelijk openbaar vervoer, looproutes en natuur, voldoende verlichting en voldoende (comfortabele) zitplaatsen*
Verbondenheid	*De mate waarin iemand zich gesteund, geliefd en gewaardeerd voelt, zich verbonden voelt met anderen en het gevoel heeft wat te betekenen voor anderen*
Financiële zekerheid	*De mate waarin iemand kan voorzien in basisbehoeften en vrijheid ervaart door het kunnen bekostigen van deelname aan activiteiten, vakanties, producten, diensten en extraatjes*
Ervaren gezondheid	*De mate waarin iemand zich niet beperkt voelt in zijn/haar doen en laten door zijn/haar fysieke, mentale of cognitieve aandoeningen of symptomen (zoals bijv. pijn, vermoeidheid, functieverlies, of verlies van zicht of gehoor)*
Veerkracht	*De mate waarin iemand een positieve houding heeft ten aanzien van zijn/haar leven en zich kan aanpassen, tegenslagen kan accepteren en 'het beste van het leven maakt'*
Emotioneel comfort	*De mate waarin iemand gemoedsrust heeft (zich tevreden voelt en kalm en vrij van zorgen is) en vrolijk/gelukkig is (plezier in het leven ervaart, het leven omarmt en kleine dingen waardeert)*

Tabel 3 De 6 additionele domeinen van de Extended Quality Tool

Het betreft de volgende domeinen: toegankelijkheid en (leeftijds)vriendelijkheid van de buurt, verbondenheid, financiële zekerheid, ervaren gezondheid, veerkracht en emotioneel comfort. 'Verbondenheid' is toegevoegd omdat tijdens het proces vastgesteld werd dat niet alle sub-thema's van sociaal contact pasten onder door de ASCOT domeinen 'sociaal contact' en 'tijdsbesteding'. Onder andere de sub-thema's 'genieten van een band met familie'; 'ervaren dat mensen om je geven' en 'je geliefd voelen' werden onvoldoende gedekt. 'Veerkracht' is afgeleid van het domein 'Attitude en Aanpassingsvermogen'. Dit domein gaat met name om 'positief blijven bij tegenslag', dat beter gevat wordt door het woord veerkracht. Besloten is om 'Spiritualiteit' niet als additioneel domein toe te voegen, omdat de invulling hiervan zeer persoonlijk is. Bovendien vonden we bij geen van de drie onderzochte diensten ervaren invloed op dit domein.

Na het vaststellen van de additionele domeinen is de passende formulering vastgesteld van zowel de vraag als de vier responseopties, op een wijze die aansluit bij de formuleringen van de ASCOT-NL. De antwoordopties zijn dus ook geformuleerd in termen van *capabilities*. De vraag bij het domein 'Verbondenheid" luidt bijvoorbeeld: Welke van de volgende uitspraken beschrijft het best hoe verbonden u zich voelt met anderen? De antwoordopties zijn: 1) Ik voel me zo verbonden met anderen als ik wil;

2) Ik voel me voldoende verbonden met anderen; 3) Ik voel me onvoldoende verbonden met anderen; 4) Ik heb het gevoel er alleen voor te staan.

Toepassingsmogelijkheden van de EQLT in de zorg
Terwijl de ASCOT met name geschikt is voor economische evaluaties, kan de EQLT gebruikt kan worden voor verschillende kwaliteitsdoeleinden De EQLT kan flexibel worden ingezet voor het in kaart brengen en monitoren van KvL van ouderen in specifieke situaties waarin zij zorg ontvangen: afhankelijk van de context kunnen de relevante domeinen uit de EQLT worden geselecteerd, waardoor de EQLT als een adaptieve tool kan worden gebruikt. Als we bijvoorbeeld willen weten of een bepaalde dienst beoogt minder zorgen te geven voor de oudere, kan het domein ‘Emotioneel comfort’ worden geselecteerd. Ook het domein ‘Gezondheid’ kan relevant zijn; daarbij gaat het in de EQLT, anders dan in de EQ-5D, niet om specifieke aspecten van gezondheid, maar om de algemeen ervaren gezondheid, in relatie tot wat mensen zelf als ideaal zien.

De EQLT zou daarnaast gebruikt kunnen worden voor het vaststellen van individuele behoeften als basis voor dienstverlening. De clinicus kan het instrument gebruiken in de praktijk door toe te passen in de gesprekscontext. Het instrument fungeert dan als een screeningstool: welke domeinen van KvL zijn voor dit individu van belang en op welk niveau scoort deze persoon zichzelf in zijn specifieke setting? Op basis van de uitkomsten kan in dialoog tussen de oudere en de zorgverlener worden nagegaan welke aspecten een rol spelen bij de score op de domeinen. Op deze manier kan een persoonlijk KvL-narratief ontwikkeld worden. Vervolgens kan de EQLT ingezet worden om de behoefte van de persoon op relevante domeinen te bepalen. Op deze manier zou de EQLT een hulpmiddel kunnen zijn bij het opstellen van een zorgplan waarin de waarden en wensen van de oudere zelf centraal staan. Tot slot zou de EQLT gebruikt kunnen worden om de behoefte van de persoon op relevante domeinen te monitoren. Op deze wijze kan in kaart worden gebracht welke veranderingen optreden bij de ouderen, en of eventueel andere domeinen relevant zijn geworden op een later tijdstip.

De EQLT is gebaseerd op een uitgebreide review. Doordat de interviews met ouderen zelf de basis vormden voor de aanvullende 6 items is een belangrijk aspect van content validiteit meegenomen in de EQLT. Wel is het noodzakelijk dat andere aspecten van de content validiteit (zoals begrijpelijkheid van de items) en betrouwbaarheid nader onderzocht worden. Tevens is onderzoek nodig naar de implementeerbaarheid in de gesprekscontext.

Discussie

In dit artikel hebben we de ontwikkeling en de inhoud van de ASCOT-NL en de EQLT beschreven, en toepassingsmogelijkheden in de evaluatie van zorg belicht. Beide instrumenten beogen effecten van zorg op KvL van thuiswonende ouderen te meten op meerdere relevante domeinen. De ASCOT-NL kent acht domeinen, de EQLT in totaal 14 domeinen (acht uit de ASCOT-NL in Tabel 1 plus de zes additionele domeinen in Tabel 3). De acht domeinen van de ASCOT-NL zijn gebaseerd op de doelen van sociale ondersteuning en zorg; de zes aanvullende domeinen van de EQLT zijn gebaseerd op empirisch onderzoek naar KvL vanuit het perspectief van thuiswonende ouderen en onderzoek naar de manier waarop zorg kan bijdragen aan KvL.

De ASCOT-NL kan gebruikt worden in economische evaluaties van zorg aan ouderen in de thuissituatie; de ontwikkelde preferentiewaarden stellen onderzoekers in staat om QALYs te berekenen die breder zijn dan gezondheid alleen. Uit een klinimetrische analyse van de ASCOT-NL in vergelijking met de ASCOT-UK (ongepubliceerde data) bleek dat beide ASCOT versies sterk correleerden, zowel voor utiliteitsscores na 12 maanden (correlatie 0.98) als voor verschilscores over 12 maanden (correlatie 0.95). Omdat de ASCOT-NL nog verder gevalideerd moet worden in empirische studies, raden we onderzoekers aan om naast de ASCOT-NL ook de EQ-5D-5L mee te nemen om QALYs te berekenen.[5]

De EQLT kan gebruikt worden om indien relevant één of meerdere dimensies aan de ASCOT-NL toe te voegen zodat ook uitkomsten op deze domeinen in kaart kunnen worden gebracht. Daarbij moet wel bedacht worden dat er geen preferentiewaarden beschikbaar zijn voor deze additionele dimensies en dat de EQLT als zodanig niet gebruikt kan worden voor economische evaluaties. De EQLT zou tevens gebruikt kunnen worden op individueel niveau, in het bijzonder om de relevantie domeinen van KvL in kaart te brengen als startpunt voor een gesprek over zorgbehoeften van cliënten.

De gepresenteerde instrumenten zijn gebaseerd op uitvoerig onderzoek. Een sterk punt van de ASCOT is de theoretische verbinding met de *Capability Approach*. Ook empirisch is de waarde van de ASCOT breed onderzocht. De ASCOT-NL is gevalideerd voor de Nederlandse context. De EQLT is gebaseerd op een uitgebreide review. Doordat de interviews met ouderen zelf de basis vormden voor de aanvullende 6 items is een belangrijk aspect van content validiteit meegenomen in de EQLT. Wel is het noodzakelijk dat andere aspecten van de content validiteit (zoals begrijpelijkheid van de items) en betrouwbaarheid nader onderzocht worden. Tevens is onderzoek nodig naar de implementeerbaarheid in de gesprekscontext.

Vanuit het perspectief van economische evaluaties is een centrale vraag in de evaluatie van zorg waar beschikbare capaciteit en geld voor moeten worden ingezet. Hierbij gaat het om een afweging tussen de kosten en de baten, waarbij de baten vaak worden uitgedrukt in termen van KvL. Als het gaat om KvL van ouderen, moet een breder perspectief op KvL worden gehanteerd dan een strikte focus op gezondheid omdat de gezondheid van ouderen vaak niet te verbeteren is. Het doel van zorg is eerder stabilisering en voorkomen of vertragen van achteruitgang in gezondheid. Bovendien blijken andere domeinen van KvL, zoals autonomie en relaties, voor ouderen van groot belang te zijn.[12] Bij het verdelen van middelen en geld tussen verschillende zorgvormen of tussen meerdere aanbieders van zorg dient rekening te worden gehouden met de invloed van de betreffende diensten op KvL in brede zin en moet de focus dus niet liggen op de gezondheidgerelateerde aspecten van kwaliteit van leven. Om deze bredere aspecten van KvL te kunnen evalueren dient een instrument te worden gebruikt dat hiervoor geschikt is. De ASCOT-NL kan hier een nuttige bijdrage leveren. Verder onderzoek is nodig waarin de uitkomsten van de ASCOT-NL worden vergeleken met die van andere instrumenten, zowel de EQ-5D als instrumenten die een breder perspectief op KvL belichamen, zoals de ICECAP-O.

Tevens is een belangrijke politieke vraag wat wij zien als doelen van zorg en wie dat bepaalt. Laten we dat aan zorgorganisaties, willen we dat de overheid centraal verplichte uitkomsten opstelt of gaan we uit van wat de oudere zelf belangrijk vindt? De ASCOT-NL en de EQLT beogen handvatten te bieden voor het laatstgenoemde perspectief. Als het gaat om verdeling van beschikbare middelen, speelt nog een vraag. Moet ingezet worden op het verbeteren van KvL voor zoveel mogelijk mensen, of op het bevorderen van mogelijkheden van diegenen die onder een KvL-minimum dreigen te geraken?[20] Deze vragen worden door de hier besproken instrumenten zelf niet beantwoord; de resultaten van de toepassing van de instrumenten kunnen wel gebruikt worden als uitgangspunt voor een maatschappelijke discussie over verdeling van zorg.

De verdeling van middelen tussen verschillende vormen van zorg wordt bemoeilijkt doordat de effecten op de verschillende domeinen van KvL zowel positief als negatief kunnen zijn. Een bepaalde vorm van ondersteuning, zoals bijzonder vervoer, kan enerzijds de autonomie van de cliënt bevorderen, doordat deze de mogelijkheid krijgt anderen te bezoeken, maar tegelijkertijd de autonomie beperken doordat de cliënt afhankelijk is van vastgestelde rijtijden. In de evaluatie dient met dergelijke tegengestelde effecten rekening te worden gehouden.

Daarnaast kan er sprake zijn van overlap tussen de domeinen.[12] Zoals blijkt uit het voorbeeld van bijzonder vervoer kunnen effecten op een domein (autonomie) uitstralen naar een ander domein (relaties). Zowel de mogelijkheid van tegengestelde effecten op één domein, als interferentie tussen domeinen houdt in dat resultaten van evaluatieonderzoek met vragenlijsten interpretatie vereist. Daarbij kan gebruik worden gemaakt van kwalitatieve onderzoeksmethoden, bijvoorbeeld aanvullende interviews of focusgroepen met betrokken cliënten en professionals.

Besluitvorming over verdeling van zorg vereist genuanceerde afwegingen en maatschappelijke discussie. Wat zien wij als de best mogelijke uitkomsten? De ASCOT-NL en de EQLT kunnen daarbij steun bieden door inzicht te geven in door ouderen zelf ervaren effecten van zorg op een breed scala van domeinen van KvL.

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Bijlage: Handleiding en domeinen EQLT

Handleiding EQLT

De EQLT bestaat uit de 8 domeinen van de Nederlandse vertaling van de ASCOT (de ASCOT-NL) en 6 aanvullende domeinen. De volledige ASCOT-NL is te vinden op https://www.pssru.ac.uk/ascot/translations/ en is vrij verkrijgbaar na registratie via https://www.pssru.ac.uk/ascot/licensing/.

De domeinen in de ASCOT-NL zijn: *regie over het dagelijks leven, persoonlijke verzorging, eten en drinken, persoonlijke veiligheid, sociaal contact, tijdsbesteding, verzorgde woning* en comfort en *waardigheid*.
De aanvullende domeinen in de EQLT vragenlijst zijn: *toegankelijkheid en (leeftijds) vriendelijkheid van de buurt; verbondenheid; financiële zekerheid; ervaren gezondheid; veerkracht; emotioneel comfort.* Elk domein heeft een eigen vraag.

De aanvullende domeinen zijn gebaseerd op analyse van uitkomsten van een systematische review naar aspecten die belangrijk zijn voor de kwaliteit van leven van ouderen. Niet elk aspect van kwaliteit van leven is te beïnvloeden (door zorg/welzijnsorganisaties/gemeenten) en sommige aspecten zijn niet altijd het primaire doel van zorg, maar interventies kunnen wel neveneffecten hebben op al deze aspecten van kwaliteit van leven. Daarom zijn de voor ouderen zelf relevante aspecten die niet in de ASCOT-NL aan bod komen toegevoegd als domeinen in de Extended Quality of Life Tool.

Het is aan de gebruiker zelf om te kiezen welke domeinen meegenomen worden in de evaluatie van interventies voor ouderen. De vragenlijst kan gebruikt worden om uitkomsten te evalueren en te monitoren, maar ook als gespreksinstrument om aspecten van kwaliteit van leven te identificeren die voor een specifieke cliënt van belang zijn. Vervolgens kan bekeken worden op welke manier zorg hieraan een bijdrage zou kunnen leveren.

Voor elk domein is er voor de respondent de mogelijkheid om aan te geven wat hij/zij verstaat onder (on)voldoende vervulling van het betreffende aspect van kwaliteit van leven. Dit betekent dat er een ideale toestand gedefinieerd is als beste optie en dat de respondent aangeeft in hoeverre aan deze toestand wordt voldaan en in hoeverre de respondent zou willen dat in hogere mate aan deze toestand wordt voldaan. In deze handleiding wordt omschreven wat per domein de verschillende antwoordopties betekenen.

1. Toegankelijkheid en (leeftijds)vriendelijkheid van de buurt

Definitie domein: de mate waarin iemand zijn/haar buurt als toegankelijk en (leeftijds) vriendelijk ervaart, met bijv. voldoende, veilige en goed bereikbare voorzieningen, voldoende en toegankelijk openbaar vervoer, looproutes en natuur, voldoende verlichting en voldoende (comfortabele) zitplaatsen.

Niveau	Betekenis
Ideale toestand	*Persoon voelt zich vrij om naar buiten te gaan, voelt zich prettig in de buurt en kan de plekken bereiken die zij wil*
Geen behoeften	*Persoon voelt zich niet belemmerd om op pad te gaan*
Enige behoeften	*Persoon ervaart enige beperkingen in de buurt om te gaan en staan waar zij zou willen*
Sterke behoeften	*Persoon is niet in staat het huis uit te gaan*

Vraag: 1. Welke van de volgende uitspraken beschrijft het best in hoeverre u uw buurt als toegankelijk en (leeftijds)vriendelijk ervaart?

Met toegankelijk en (leeftijds) vriendelijk bedoelen we bijvoorbeeld voor ouderen toereikende voorzieningen, openbaar vervoer en inrichting van de openbare ruimte zoals voldoende groen, verlichting en zitplaatsen en toegankelijke paden.

1. Mijn buurt is zo toegankelijk en prettig als ik wil
2. Mijn buurt is voldoende toegankelijk en prettig
3. Mijn buurt is onvoldoende toegankelijk en prettig
4. Ik ervaar zoveel beperkingen in de buurt dat ik het huis niet uit kom

2. Verbondenheid

Definitie domein: de mate waarin iemand zich gesteund, geliefd en gewaardeerd voelt, zich verbonden voelt met anderen en het gevoel heeft wat te betekenen voor anderen.

Niveau	Betekenis
Ideale toestand	*Persoon ervaart en biedt zoveel steun, liefde en/of verbondenheid als zij wil, en voelt zich zo belangrijk en gewaardeerd als zij wil.*
Geen behoeften	*Persoon voelt zich voldoende gesteund, geliefd en gewaardeerd, en heeft het gevoel ook iets voor anderen te betekenen*
Enige behoeften	*Persoon voelt zich onvoldoende gesteund, geliefd en gewaardeerd, en heeft het gevoel niet genoeg voor anderen te kunnen betekenen*
Sterke behoeften	*Persoon heeft het gevoel er alleen voor te staan, voelt zich niet verbonden met anderen en/of heeft het gevoel anderen of de maatschappij voornamelijk tot last te zijn.*

Vraag 2: Welke van de volgende uitspraken beschrijft het best hoe verbonden u zich voelt met anderen?

Met verbondenheid bedoelen we in hoeverre u zich gesteund, geliefd en gewaardeerd voelt, en het gevoel heeft wat voor anderen te kunnen betekenen.

1. Ik voel me zo verbonden met anderen als ik wil
2. Ik voel me voldoende verbonden met anderen
3. Ik voel me onvoldoende verbonden met anderen
4. Ik heb het gevoel er alleen voor te staan

3. Financiële zekerheid

Definitie domein: De mate waarin iemand kan voorzien in basisbehoeften en vrijheid ervaart door het kunnen bekostigen van deelname aan activiteiten, vakanties, producten, diensten en extraatjes.

Niveau	Betekenis
Ideale toestand	*Persoon heeft de financiële vrijheid om van het leven te genieten en in alle wensen te voorzien*
Geen behoeften	*Persoon maakt zich geen zorgen over geld en heeft voldoende geld om in basisbehoeften te voorzien en dingen te kunnen ondernemen*
Enige behoeften	*Persoon maakt zich zorgen over geld en heeft weinig financiële ruimte*
Sterke behoeften	*Persoon voelt zich belemmerd door te weinig inkomen of onvoldoende middelen en maakt zich zorgen over het betalen van rekeningen en de (toekomstige) financiële situatie.*

Vraag 3: Welke van de volgende uitspraken beschrijft uw financiële situatie het best?

Met financiële situatie bedoelen we ook andere materiele zaken zoals bekostigen van deelname aan activiteiten, vakanties, producten, diensten en extraatjes

1. Ik heb de financiële vrijheid om te doen wat ik wil
2. Ik heb voldoende geld en maak me geen zorgen over mijn financiën
3. Ik maak me soms zorgen over mijn financiën
4. Ik heb te weinig geld en maak me ernstig zorgen over mijn financiën

4. Ervaren gezondheid

Definitie domein: De mate waarin iemand zich niet beperkt voelt in zijn/haar doen en laten door zijn/haar fysieke, mentale of cognitieve aandoeningen of symptomen (zoals bijv. pijn, vermoeidheid, functieverlies, of verlies van zicht of gehoor).

Niveau	Betekenis
Ideale toestand	*Persoon voelt zich gezond en is zo actief als zij wil*
Geen behoeften	*Persoon voelt zich niet beperkt door zijn/haar pijn en /of andere klachten*
Enige behoeften	*Persoon ervaart enige pijn en/of andere klachten en voelt zich enigszins beperkt*
Sterke behoeften	*Persoon voelt zich beperkt en niet gezond, heeft veel last van pijn en/of andere klachten*

Vraag 4: Als u denkt aan uw gezondheid, welk van de volgende uitspraken beschrijft uw situatie dan het best?

Met gezondheid bedoelen we de mate waarin u zich niet beperkt voelt in doen en laten door fysieke, mentale of cognitieve aandoeningen of symptomen (zoals bv pijn, vermoeidheid, functieverlies, of verlies van zicht of gehoor)

1. Ik voel me zo gezond als ik wil
2. In het algemeen voel ik me voldoende gezond en niet beperkt
3. Ik voel me onvoldoende gezond en enigszins beperkt
4. Ik voel me helemal niet gezone en ernstig beperkt

5. Veerkracht

Definitie domein: De mate waarin iemand een positieve houding heeft ten aanzien van zijn/haar leven en

- *zijn/haar situatie en wat zijn/haar overkomt kan accepteren,*
- *zijn/haar standaard aan kan passen aan wat acceptabel of belangrijk is*
- *en/of in staat is om zijn/haar gedrag aan te passen aan tegenspoed (bijvoorbeeld door het gebruik van hulpmiddelen, hulp vragen of gewoonten aanpassen).*

Oftewel, in hoeverre iemand het beste van het leven maakt.

Niveau	Betekenis
Ideale toestand	*Persoon maakt het beste van zijn/haar leven en kan met moeilijke omstandigheden omgaan zoals zij wil*
Geen behoeften	*Persoon kan voldoende omgaan met tegenslagen*
Enige behoeften	*Persoon heeft moeite achteruitgang en tegenspoed te accepteren*
Sterke behoeften	*Persoon voelt zich machteloos en hulpeloos.*

Vraag 5: Welke van de volgende uitspraken beschrijft het best in hoeverre u zich staande kunt houden bij tegenslag?

1. Ik kan mij goed staande houden bij tegenslag
2. Ik kan mij voldoende staande houden bij tegenslag
3. Ik kan mij onvoldoende staande houden bij tegenslag
4. Ik voel me machteloos bij tegenslag

6. Emotioneel comfort

Definitie domein: De mate waarin iemand gemoedsrust heeft (zich tevreden voelt en kalm en vrij van zorgen is) en vrolijk/gelukkig is (plezier in het leven ervaart, het leven omarmt en kleine dingen waardeert).

Niveau	Betekenis
Ideale toestand	*Persoon voelt zich zo gelukkig als zij wil, geniet van het leven en is vrij van zorgen*
Geen behoeften	*Persoon ervaart (in het algemeen) plezier en gemoedsrust*
Enige behoeften	*Persoon voelt zich wat somber of gespannen en/of maakt zich zorgen*
Sterke behoeften	*Persoon voelt zich angstig, gestrest, verdrietig of neerslachtig en is bang voor de toekomst*

Vraag 6: Welke van de volgende uitspraken beschrijft het best hoe gelukkig u zich voelt?

1. Ik voel me zo gelukkig als ik wil
2. Ik ervaar voldoende plezier en heb weinig zorgen
3. Ik voel me wat somber, gespannen of maak me zorgen
4. Ik voel me angstig, gestrest of neerslachtig

CHAPTER 6

Implementing a broad quality of life tool for determining care wishes and needs of older adults living at home

Van Loon, M.S., Widdershoven, G.A.M., Van Leeuwen, K.M., Bosmans, J.E., Metselaar, S., Ostelo, R.W.J.G

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Abstract

The aim was to investigate the views of stakeholders on the practical relevance of a broad quality of life (QoL) outcome tool for care in older adults: the Extended Quality of Life Tool (EQLT).

We conducted individual interviews and focus groups with a variety of stakeholders involved in the care for older adults which were analyzed using a framework analysis.

Stakeholders considered relevant: focus on the client perspective; perspective on QoL broader than health; the possibility to take diversity into account; and the possibility to determine a minimum level of QoL. Three facilitators for implementation of the tool were mentioned as well as four barriers.

The EQLT can support conversations with clients about their needs and wishes, thus enabling decisions about care services based on a broad set of domains of QoL. Implementation of the tool should take into account the facilitators and barriers identified in the current study.

Key words: older adults at home, care services, quality of life assessment, implementation

Introduction

In the past decade, the number of older adults living and receiving care at home has increased dramatically (Tang & Lee, 2010, Sonnega et al., 2017). Governments provide home care services to improve overall quality of life (QoL) (Celani et al., 2017), to help maintain a basic standard of living for older adults, and to decrease medical costs (Ryburn et al., 2009). Currently, benefits of care are often measured using health-related QoL measures (Herdman et al., 2005). The EuroQol questionnaire (EQ-5D)(The EuroQoL group, 1990), for instance, is exclusively focused on health-related aspects of QoL (Al-Janabi., 2012; Coast et al., 2008). However, in older adults, these health aspects of QoL often cannot be (substantially) improved. Other aspects of QoL, such as being able to manage one's situation and feeling supported by others, are therefore important to be included as relevant outcomes of care. In short, a broader perspective on QoL seems required in determining quality of care in this context.

The ASCOT (Adult Social Care Outcomes Toolkit) was developed in the United Kingdom to measure outcomes of social care in terms of QoL from a broader perspective than health alone (Netten et al, 2012). The ASCOT-SCT4 consists of eight domains; *control over daily life; personal cleanliness and comfort, food and drink; personal safety; social participation and involvement; occupation; accommodation cleanliness and comfort,* and *dignity*. This offers the opportunity to measure and compare the outcomes of different types of care and services that do not primarily aim to improve health. Specifically, the ASCOT focuses on outcomes which are related to the goals of *social* care.

In a systematic review on older people's views on and experiences of QoL, we found that, next to the ASCOT domains, there are additional domains that older people living at home deem important (van Leeuwen et al., 2019). In addition, a qualitative study was performed to explore in more in-depth what domains were important to older adults receiving services (Van Loonet al., submitted). Using an iterative consensus procedure based on these findings, 6 additional domains were defined: *accessibility and age-friendlines of the neighbourhood; connectedness; financial security; perceived health; resilience* and *emotional comfort*. In order to assess outcomes of care in a way that also takes into account these additionals domains, we have developed a tool consisting 6 additionall QoL domains: the Extended Quality of Life Tool (EQLT). The EQLT can be used in older adults living at home to map what is relevant for their QoL, to enable a conversation about QoL and to monitor QoL.

However, the question remains whether implementation of the EQLT is feasible in practice. The hypothesis is, on the basis of the systematic review and the qualitative study, that adding domains of QoL to those of the ASCOT is relevant. Do stakeholders, i.e. care providers, client representativesor others who are well-acquainted with the practical context in which the EQLT is envisioned to be used, confirm this relevance? Furthermore, do they think this extended tool can be implemented? What could be possible facilitators or barriers according to stakeholders?

The purpose of this study was to explore how stakeholders view the relevance of the EQLT for making decisions about provision of care services, and what, in their perception, might be possible facilitators or barriers, i.e. promoting and limiting factors, for the implementation of the tool.

Methods

To address the research questions, we organized interviews and focus groups with different stakeholders in the Netherlands. Stakeholders included professionals involved in providing care to older people living at home, client representatives, managers and policy officers of care institutions and policy officers of healthcare purchasing organizations. Given the explorative nature of this study, purposive sampling was used to reach a broad range of diverse stakeholders. Ethics approval was obtained from the METC VUMC Amsterdam.

Procedure

In this study, we used qualitative methods to explore the perspectives of various stakeholders. The goal of such qualitative research is to understand the world from the perspective of these stakeholders, assuming that multiple meanings and understandings of a phenomenon are likely to co-exist (Green & Thorogood, 2018 p. 16), and that knowing them may help to create usable services or instruments (Batalden et al, 2016).

Qualitative methods, especially individual interviews and focus groups, are valuable in implementation research because they can help understand how implementation can be successful or what can be barriers (Hamilton & Finley, 2019). Our analysis approach combined deductive and inductive elements; the transcripts were summarized and grouped into themes, based on the topics from the research question and topic guide, which was based on previous research. We distinguished between (1) perceived value of the tool; (2) facilitators for implementation; and (3) barriers for implementation. The framework developed from previous research was used to identify factors influencing implementation (Hamilton & Finley, 2019, Hamilton et al., 2018).

Stakeholders were first approached through affiliated partners of the research project. Secondly, other organizations were approached by e-mail, explaining the goal and procedure of the study. At the beginning of the interview, respondents were verbally asked for consent to record the interview and it was explained that the content of the interview was confidential and reported data would be presented anonimously.

Data collection

Interviews were semi-structured, i.e. open, but guided by a topic list. The topic list was based on the EQLT domains ([author information removed]et al., submitted), complemented with questions about goals of care services for older adults and possible facilitators and barriers in implementing an instrument such as the EQLT. The topic list aimed to achieve coverage of the topics throughout the different conversations. Interviews lasted between 50 and 80 minutes.

In addition, we conducted three focus group interviews. The first focus group was conducted during a training for general practitioners. The second focus group was organized with client representatives, representing the voice of specific patient groups in aacare. During these focus group interviews we used a topic list similar to the interview topic guide. The focus groups lasted between 65-150 minutes. The third focus group was organized during a seminar discussing outcomes of a related project. This focus group lasted 75 minutes. The first two focus groups were recorded and transcribed, the last meeting was not recorded. During this meeting, three of the authors were present and summarized the results.

Analysis

Transcripts of the interviews and the first two focus groups, and the summary of the third focus group, were reviewed using framework analysis (Srivastava & Thomson, 2009). Three researchers (ML, GW, RO) analyzed the transcripts independently and discussed their findings. Through an inductive, iterative process, discussing disagreements until agreement was reached, themes were identified.

Results

Sample/respondents

All respondents had experience in their field, some working in large care organizations, and other in small care organizations such as a general practice. Also, respondents from health care purchasing organizations were included, as well as client representatives from an organization representing older adults. The organizations were located in urban area's in the Netherlands.

The sample consisted of seven respondents for interviews(five female, two male). Three respondents (R1-R3) worked for care organizations providing services at home for older adults, and four respondents (R4-R7) worked for healthcare purchasing organizations. The first focus group had five participants (R8-R12) working in general practice(four female, one male). The second focus group had five participants (R13-R17) who were client representatives (three female, two male). The third focus group had nine participants (R18-R27) working for care organizations providing services for older adults. More detailed information about the respondents can be found in Appendix 1.

Findings

Guided by the research questions we identified several themes regarding the relevance of the tool (1), and facilitators and barriers for implementation (2).

1. Relevance

Concerning the relevance of the EQLT, we identified four themes on the basis of both interviews and focus groups: (1) a focus on client perspective; (2) looking broader than health; (3) the possibility to take diversity into account; (4) the possibility to determine a minimum standard.

A focus on client perspective

Respondents said it is important that clients can determine themselves what QoL means to them:

- *'I cannot speak for someone else or say what another person understands as good care or good life. I mean, I have visited many people in their house and sometimes I think: 'Gosh, I wouldn't want to live in that way', but for some people certain things can provide comfort or be important [..] everyone has their own standards of living' (R5)*

Correspondingly, ideally, the client him- or herself can use the instrument to determine care needs. If necessary, informal care givers can be involved when completing the instrument, for instance by reading out the questions or filling in the instrument together.

- '*The informal carer could read [the domains and ask] 'dad, is this important for you?'* (R3)

Looking broader than health

According to respondents, goals of care should not be too narrowly focused on health outcomes.

- *If someone has limitations, in providing care you should focus on which adaptations you can make to account for these limitations. […] To maintain the quality in people's life. (R12)*

A tool addressing more than health, such as the EQLT, can help to understand the needs of a client from a broad perspective on QoL.

- *'If someone visits the GP, well the GP has 10 minutes, I have a headache – let's prescribe a pill [..] Maybe the headache will disappear, but if the headache springs from the fact that someone is stressed out because he has no financial security… In that case you could continue to prescribe pills, but the problem will not be solved' (R5)*

Taking into account diversity

A further aspect of the EQLT that according to respondents contributes to its relevance is that it takes into account the fact that people are different. Respondents said the meaning of QoL can vary greatly from person to person.

- *'Diversity in older adults is immense [..] what is required to enable them to participate in society just like everyone else? That is very much tailor-made, depending on someone's strength, depending on the need for support' (R3)*

This implies that certain domains are more important for one person than for another, or that the desired level of functioning in a specific domain may differ from person to person. A person's life story can influence their preferences for specific aspects of QoL.

- *'If someone was very active in the past, had a big and rich friend groups, and now is at home alone, the question might be: is this person really happy?'* (R5)

Providing a minimum standard

Although respondents emphasize that people are different, they also believe there are certain basic domains of QoL that are important to everyone. In these domains, a minimal standard should be determined, to set a minimum outcome treshold of care.

- *'Control over daily life and food and drink are really important, if that's not in order, a person literally crashes. '(R2)*
- *' [personal care] is a basic condition […] It should be present minimally' (R5)*

Having a tool that helps identifying a minimum standard of living can support interventions to maintain a basic level of QoL in certain domains.

- *'There are things you wouldn't want to impose upon people. But being in control and food and drink, those [domains] can provide reasons for intervention: we have to interfere here if it's not going well' (R11)*

2. Facilitators and barriers for implementation

Facilitators

Regarding facilitators for implementation of the EQLT, three themes were identified: (1) the attractiveness of the tool as guidance for conversation; (2) its flexibility; (3) fostering a joint learning process.

Guidance for conversation

Several respondents noted that there is a need for an instrument that can serve as a guidance to structure and inspire a conversation between client and caregiver, as well as a dialogue between (teams of) caregivers. A list with QoL domains can help to clarify what is important for older persons and a dialogue between a caregiver and an older adult can shed light on how he or she perceives and values these domains in the context of QoL, while also taking into account the responses on the specific questions (domains).

- *'Often people cannot assess properly [what kind of help they need]. After a good conversation, we can give advice to someone which domain could be supported and how.'(R3)*

Another aspect that respondents mention is that a conversation about QoL is needed to fully understand what the client means by a score on a specific domain; simply going over the domains as identified in the EQLT and asking a care receiver to 'tick the boxes' would not work.

- *'[The tool is] a guidance for a conversation, you cannot really use it as a fixed standard' (R5)*

Flexibility

Respondents explained that they need an instrument that allows them to be flexible. This helps them in providing personalized care, i.e. care that is tailored according to the wishes and needs of an individual client. By taking into account the various domains of the EQLT, a personal care plan can be designed for each client.

- *'The home nurse may look a little further [than the client's health status]. Make a personal plan, be it care or welfare.'(R5)*

A tool that supports flexibility in establishing care goals can also enable clients and caregivers to make decisions together throughout care trajectories, in which different types of care are received, depending on the situation and condition of the client. This may start with home care and end with institutional care, for instance.

- '*an instrument that moves with the client throughout the chain*' (R7).

Fostering a joint learning process

According to respondents, the EQLT can be used to learn from other care institutions. Within a care institution, outcomes of the tool may give insight into aspects of care that can be improved.

- '*What can be done to improve, what is going well, what isn't, and how can we learn?'(R6).*

Respondents from healthcare purchasing organizations emphasized the importance of fostering learning between care organisations.

- '*We bring organizations in contact with each other, in order for them to learn. Enabling them to become better..'(R4)*

Using the EQLT, both as a conversation and monitoring tool, may support this joint learning process.

Barriers

Next to facilitators, four barriers, i.e. limiting factors, in implementing the EQLT were identified: (1) the tool may distract attention from core activities; (2) there may be a lack of time; (3) professionals may have resistance to the evaluation of care outcomes; (4) results may not be useful because of an absence of adequate funding.

Distraction from focus on core activities

A potential barrier for implementation of a tool like the EQLT is that it contains many domains. Some domains might be more relevant for a specific care organization than others. Respondents saw difficulties in deciding who determines which domains should be targeted by which care service. Also, the question was raised whether it was within the span of control – or the responsibility – of a specific care service to deal with certain domains.

- *'Dignity, control, those are very important. But some other [domains] have less* *significance for us. […] Finances can determine how you feel, but a care organization cannot fix [finances] directly.' (R5)*

Lack of time

As a second barrier, respondents mention lack of time. There is (often) not enough time allocated to have a lengthy conversation about QoL with clients, and to adequately address all domains that are included in the EQLT.

- '*In practice, […] there is lack of time to fully understand social issues' (R3)*
- '*Time is limited because caregivers have to produce, they have to do things as fast as possible' (R3)*

Resistance to evaluating outcomes of care

Another barrier is resistance to evaluating outcomes of care. Respondents question whether tools which measure outcomes are really helpful in getting insight in what people need. Although the questions in the EQLT are quite concrete, it is not always clear what the answers mean.

- *[If the neigborhood is not experienced as accessible enough] 'what does that mean? There is no busstop in front of someone's house? There is no public space? There is a lack of green areas?' (R5)*

Respondents also mention that many instruments are used already. Adding a new tool might be redundant, or even complicate evaluation processes.

- *'There are also other instruments to assess the outcomes of elderly care [..]so there is an incredible mass of measurements' (R11)*

No adequate funding

A final barrier that was mentioned is the lack of adequate funding to provide the care needed. Respondents indicated the current system of funding is not suitable to meet or anticipate on caring needs, both because of a lack of money and because of allocation decisions.

- *'Very often there is also no basis for payment to do anything in an early phase. So you often also see that people think about the money instead of what is needed in terms of content.'(R3)*
- *'If you do an intervention, you get paid for it. Knee surgery costs so much. Whereas, for example, if you were use value-driven purchasing, you would assess whether someone can walk well without pain. And then you manage that outcome, both with physio in advance in the process, and with GP and rehabilitation later. And then you should give a bag of money which they can divide among themselves.'(R2)*

Discussion

This study investigated the relevance of a broad instrument for monitoring care for older adults living at home, specifically the EQLT, as well as limiting and promoting factors concerning the implementation of this tool.

Concerning the relevance, we identified four themes; (1) the tool provides a focus on the perspective of the client; (2) it enables to assess aspects of QoL broader than health; (3) it helps taking into account diversity; (4) it can be used to define a minimum standard of QoL. Three facilitators for implementation of the tool were described by respondents: (1) the attractiveness of the tool as guidance for conversation; (2) the flexibility of a tool; (3) fostering of a joint learning process. Also, four barriers or obstacles were identified: (1) the tool may distract attention from core activities; (2) there may be a lack of time; (3) professionals may have resistance to evaluating care outcomes; (4) results may not be useful because of an absence of adequate funding.

The relevance of the EQLT as identified by the respondents is in line with the central ideas behind the tool. Its two constitutive elements, i.e. the ASCOT and the extra domains of QoL (based on the systematic review (Van Leeuwen et al., 2019) and the qualitative study ([author information removed]et al., submitted)), both depart from the views of older people themselves on QoL. The Capability Approach can be used as framework to put the values and diversity of people at the center and move away from a health focused view (Gopinath, 2018, Meijering et al., 2019). In this way, the CA can help to understand what really matters to older adults who receive care. A previous study showed that the ASCOT can be regarded as an operationalization of the CA (Van Loon et al, 2018). The answer options in the additional domains of the EQLT are also in line with the CA, as they are operationalized as functionings. The results of this empirical study confirm the importance of putting the perspective of the client central, and that health is not the only important issue in life. Furthermore, the results also emphasized the importance of recognizing diversity, and defining a minimum standard of QoL.

The facilitators mentioned by our respondents are in line with the aspects that make the tool relevant according to the respondents. Since the tool focuses on what clients deem important, it can be used in a dialogue between clients and caregivers about what matters in life, and which care is needed. Shared decision making has been shown to provide many benefits for the patient, such as respect for values, preferences and needs of the patient (Barry et al. 2012; Elwyn et al., 2012). The flexibility of the tool is directly related to the client perspective. What is important for one client, may be less so for another client.

The tool can also provide a basis for learning between care institutions. Using the same broad set of domains of QoL enables comparison between care services. In this respect, the ASCOT can be regarded as providing the basic domains which should be addressed by all care services(Van Loon et al., submitted). In the EQLT, domains can be selected based on the relevance of domains for older adults in a specific situation (Van Loonet al., submitted).

Barriers for implementation, however, are also mentioned by respondents. For successful implementation, outcome measures should be 'tailored by identifying and addressing potential barriers according to the setting' (Antunes et al., 2014). The first barrier, distraction from core activities, raises the question what counts as core activities. What care organizations define as core activities may not be most relevant from the perspective of older people themselves. The development of the EQLT as an extension of the ASCOT recognizes this contrast. Whereas the domains of the ASCOT are based on the (explicit) goals of sociale care, the EQLT contains also other domains, which go beyond these official goals. From the perspective of older people themselves, the relevance of care services may sometimes be different from what organizations themselves define as goals. If person-centered care is increasingly implemented, and policy-makers increasingly adapt systems to enhance person-centered care (Moore et al., 2017), we should take their perspective seriously.

An example from another study shows that older adults living at home appreciate informal contact with their caregivers, as this contributes to their QoL in the domains of relationships and emotional comfort (Van Loonet al, submitted). The second barrier for implementation, lack of time to use a tool like the EQLT, was also found in other implementation studies (Dunckley et al., 2005, Ellen et al., 2014). This could be addressed by making professionals aware that tailoring care to the needs and wishes of the care receiver in the end may save time (Hibbard et al., 2009, Blumental et al, 2016). The third barrier, a resistance against measurements, implies that proposing a new tool will require looking critically at existing tools. Additionally, sceptical attitudes from professionals and traditional structures are found in other studies as barriers for implementation (Moore et al., 2017). The fourth barrier, no adequate funding for early intervention, is related to the current payment system in health care and social care. This is not easily solved.

A strength of this study is that data were collected through interviews and focus groups. Combining these methods, and including a variety of stakeholders, enabled us to study the topic from different perspectives. A weakness is that one focus group was not recorded. This could influence the accuracy of the data analysis. However, the non-recorded focus group was attended by multiple researchers and findings were meticulously reported afterwards. The attending researchers discussed the report and agreed on the content. Furthermore, although data saturation was obtained to a large extent, the number of respondents included in this study was still relatively small (27 in total). Therefore, these results are not generalizable nor exclusive. This qualitative study sought to explore the implementation of the EQLT in a local population in order to come to first insights in the value of the EQLT and facilitators and barriers for implementation. Generalizability of the results will require further research in other contexts and with other populations, as well as the synthesis of various (qualitative) data (Leung, 2015). This study focused on the perspective of professionals and client representatives. A next step is to explore the usability and the validity of the EQLT, including the perspective of older adults.

Conclusions

Given the growing need for providing care to older people living at home, it is important to determine how care services can contribute to their QoL. The results of this study highlight the relevance of the EQLT, mainly as it has the potential to support dialogues between caregivers and clients about their needs and wishes based on a broad set of domains of QoL. This provides a basis for personalized care, i.e. care in which people have choice and control over the way their care is planned and delivered. It also promotes the recognition that, for many people, their needs go beyond purely medical issues. The EQLT may help older adults living at home who deal with physical and/or mental health conditions to make decisions about the care that is needed, so they can live the life they want to live, based on what matters to them. A next step could be to structurally implement this tool in one or multiple organizations, investigating the process and effects on changes in actual care.

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Appendix

Group	Respondent	Organization	Function (professional)	Type of interview
I1	*R1*	*General practice*	*Geriatric nurse*	*Interview*
D1	*R2*	*Healthcare purchasing organization 1*	*Policy officer*	*Interview*
	R3	*Healthcare purchasing organization 1*	*Policy officer*	*Interview*
D2	*R4*	*Healthcare purchasing organization 2*	*Policy officer*	*Interview*
	R5	*Healthcare purchasing organization 2*	*Policy officer*	*Interview*
D3	*R6*	*Care organization*	*Policy officer*	*Interview*
	R7	*Care organization*	*Manager*	*Interview*
F1	*R8*	*General practice*	*General practitioner*	*Focus group*
	R9	*General practice*	*General practitioner*	*Focus group*
	R10	*General practice*	*General practitioner*	*Focus group*
	R11	*General practice*	*Nurse*	*Focus group*
	R12	*General practice*	*Nurse*	*Focus group*
F2	*R13*	*Client organization*	*Client representative*	*Focus group*
	R14	*Client organization*	*Client representative*	*Focus group*
	R15	*Client organization*	*Client representative*	*Focus group*
	R16	*Client organization*	*Client representative*	*Focus group*
	R17	*Client organization*	*Client representative*	*Focus group*
F3	*R18*	*Care organization*	*Senior researcher*	*Focus group*
	R19	*Care organization*	*Teammanager*	*Focus group*
	R20	*Care organization*	*Client manager*	*Focus group*
	R21	*Care organization*	*Policy officer*	*Focus group*
	R22	*Care organization*	*Manager*	*Focus group*

	R23	*Care organization*	*Manager*	*Focus group*
	R24	*Care organization*	*Project manager*	*Focus group*
	R25	*Care organization*	*Therapist (activities)*	*Focus group*
	R26	*Care organization*	*Manager*	*Focus group*
	R27	*Care organization*	*Therapist (group activities)*	*Focus group*

Table 1: List of respondents

CHAPTER 7

General Discussion

Introduction

This thesis aimed to establish an in-depth understanding of what is important for the quality of life (QoL) of older adults living at home and receiving professional care services, and how to assess the outcomes of this care in terms of QoL. Questions regarding this topic are: Which domains of life are relevant in assessing QoL in older adults? How can these domains be measured in order to evaluate care services and to make decisions regarding the care for older adults? To answer these questions, this thesis combined philosophical reflection on the theoretical frameworks and assumptions underlying tools for measuring outcomes of care in terms of QoL with empirical research on the perspective of older adults concerning QoL.

This thesis focused specifically on the Adult Social Care Outcomes Toolkit (ASCOT). The ASCOT is designed to evaluate outcomes of social care services from the perspective of the care receiver. It captures information about an individual's social care-related QoL in eight domains: control over daily life, personal cleanliness & comfort, food & drink, personal safety, social participation & involvement, occupation, accommodation cleanliness & comfort, and dignity (Netten et al., 2012).

The toolkit consists of different tools including the ASCOT SCT-4, a four-level self-report version from the perspective of the care receiver with four response options. Respondents are asked to assess the eight QoL domains. For example, for the control domain the question is: '*Which of the following statements best describes how much control you have over your daily life?*'. The response options are '*I have as much control as I want*', '*adequate control*', '*some control, but not enough*', and '*I have no control over my daily life*'. In this thesis, when mentioning ASCOT, we refer to the SCT-4. As part of this thesis, we developed an extension to the SCT-4 with 6 new domains. This tool is called the Extended Quality of Life Tool (EQLT), including 14 items in total; the original 8 ASCOT domains and the 6 additional domains.

In this thesis, four main questions were addressed 1) How can the ASCOT be understood from the philosophical perspective of the CA? 2) What are important aspects of QoL from the perspective of older adults living at home? 3) How can care services contribute to QoL in older adults living at home? 4) How can important aspects of QoL from the perspective of older adults be addressed in QoL instruments? Combining philosophical and empirical analysis, we aimed for a better understanding of QoL in older adults living at home. In short, the following results were reported.

Chapter 2 describes the results of a philosophical analysis on the way in which the Capability Approach (CA) is implemented in the ASCOT. Three main characteristics of the CA were discussed. First, the focus of QoL evaluation should not be on functioning, but on freedom of choice. Second, evaluation should take into account so-called 'adaptive preferences', i.e. preferences may change as people lower their expectations in situations of limited possibilities. Third, evaluation should not only address health, but also other domains of life. Based on these characteristics, it was shown that the ASCOT can be regarded as an operationalization of the CA. Our analysis showed that freedom of choice is adequately reflected in the response option 'as I want' in the ASCOT questionnaire. The problem of adaptive preferences is countered in the ASCOT by developing a standard based on preferences of the general population. Third, the ASCOT contains several domains of QoL.

Chapter 3 presented a thematic synthesis review of the meaning of QoL for older adults. Interview data from empirical qualitative studies were analyzed to distinguish aspects of QoL. The review synthesized data from 48 qualitative studies, representing the views of more than 3,400 older adults, and resulted in the identification of nine domains: autonomy, role and activity, health perception, relationships, attitude and adaptation, emotional comfort, spirituality, home and neighborhood, and financial security. The results showed that although different domains can be distinguished, these are also strongly connected; QoL should be seen as a dynamic web of intertwined domains. This study provides a systematic overview of what older adults themselves find important, providing the possibility to align goals of services with the expectations of older adults. Not all domains identified in the review are covered by the ASCOT domains. We therefore decided to develop an additional tool including these domains, the EQLT, which is discussed in Chapter 5.

In **Chapter 4**, the results of an empirical study exploring the experiences of older people living at home who received different care services were presented. More specifically, we aimed to explore how older people living at home viewed the contribution to their QoL of three types of care services – medical services, social support services and support in daily living. The ASCOT domains and the additional domains identified in the thematic review (Chapter 3) were used as framework.

The study showed that for older persons living at home, medical services, social care services and services that support daily living impact a broad range of QoL domains and sometimes have an unexpected impact as well. Medical services were found not only to restore physical health, but also to provide support in maintaining an adequate level of functioning and helping older adults to cope with their situation. Social care services and services that support daily living were found to play an important role especially in fostering autonomy and relationships, two important domains of QoL.

However, we also found that services can influence QoL in a negative way; in those cases, autonomy and freedom were diminished rather than supported. When evaluating care services this possibility of adverse effects should also be taken into account. Furthermore older adults were supported by services in ways going beyond the core tasks of professionals.

In **Chapter 5** we propose a tool, based on the ASCOT, with additions based on the results of the thematic synthesis (Chapter 3). This tool is called the Extended Quality Tool (EQLT). Additional domains not included in ASCOT are: accessibility and age-friendliness of the neighborhood; connectedness; financial security; perceived health; resilience; and emotional comfort. The EQLT consists of the 8 original ASCOT domains, combined with the 6 additional domains. The EQLT can help to understand a wide range of capabilities that are important to older adults in terms of QoL. Whereas the ASCOT can be used to evaluate care services, the EQLT can be used to identify the important domains in a specific context and serve as the point of departure for a conversation with older adults about domains of QoL that matter to them, and that should be targeted by care services. Moreover, the EQLT can be used to monitor QoL over time.

In **Chapter 6** results of an empirical study exploring the views of stakeholders on the relevance of the EQLT for practice, as well as facilitators and barriers for implementation are presented. The views of a variety of stakeholders involved in the care for older adults were investigated through individual interviews and focus groups. Stakeholders viewed four characteristics of the tool as contributing to its relevance: a focus on client perspective; looking broader than health; the possibility to take diversity into account; and the possibility to determine a minimum standard.

Three facilitators for implementation were mentioned: the tool is attractive as it can be used as guidance for conversation; it can be used in a flexible way; and it provides an opportunity for learning. Four barriers were identified: the tool may distract attention from core activities; there may be a lack of time; professionals may have resistance to measurements; results may not be useful because of an absence of adequate funding.

This final chapter discusses the results of the previous chapters, and addresses two challenges in measuring QoL using the CA in older adults living at home. The first challenge concerns the question whether QoL should be measured in different domains. How to do justice to the holistic experience of QoL when using a standardized instrument, which inevitably reduces this experience by defining a-priori various domains? Relevant in this respect is also what domains should be part of a QoL instrument; for instance: should health be a domain? A further question regards the kind of items which operationalize domains. Should the description of domains be concrete or abstract?

The second challenge concerns questions about social justice considerations in caring for older adults, their capabilities and their QoL. First, we discuss limitations in the extent to which care goals can be personalized. Second, we address the question who is responsible for caring for older adults to maintain and improve their QoL using the CA. It is proposed to move beyond the professional-client dyad in formal care and think about new ways of sharing responsibility in the future.

Quality of life and the discussion on domains

In the previous chapters, it became clear there is a need for a broad view of relevant outcomes in care, defined in terms of QoL. However, some questions remain. First, whether distinguishing domains of QoL does justice to the fact that QoL is a dynamic and intertwined concept. Should QoL be divided in different domains? Second, is health a relevant domain within QoL? The ASCOT does not include health. Older people do mention health as relevant for QoL, and perceived health is, therefore, included in the EQLT. Should health be included in a QoL instrument in this context? Third, should the domains be presented through concrete questions or in a more general way? In this respect, we will compare the ASCOT with the ICECAP-O .

Should quality of life be measured in separate domains?

In Chapter 6, we discussed the relevance of a broad instrument for measuring QoL in older adults with various stakeholders. QoL was seen by these respondents as dynamic, and experienced *as a whole* . Therefore, they questioned the use of separate domains when measuring QoL in older adults. Moreover, older adults are diverse and some might find certain aspects of QoL less relevant, such as for example a healthy lifestyle, or social contact. For them, these domains should not be part of an instrument that is used to measure outcomes care. These findings are in line with the outcomes of the thematic synthesis presented in Chapter 3. There we concluded that QoL is a dynamic web of intertwined elements, implying that it is difficult to demarcate separate domains (Van Leeuwen et al., 2019). This raises the question whether it is possible to define a set of fixed domains to measure QoL.

Amartya Sen, one of the founders of the CA, argues strongly against a set 'list of basic functionings', since different sets of functionings are relevant to QoL of different groups and in different contexts (Sen, 2005:157-159). Sen deliberately leaves open what the relative weights should be for different capabilities or functionings (Alkire et al., 2008:4). According to Sen, to account for diversity, people should be able to decide for themselves what QoL entails in their situation. Sen also rejects a list of basic capabilities, and states that the importance of democratic processes and the centrality of self-determination in liberal philosophy plea against specifying what 'the good' is or what a good life consists of (Sen, 2009). According to Sen, selecting relevant capabilities should be done during a democratic process, not by theoretical analysis (bid).

Martha Nussbaum, however, disagrees with Sen, and presents a list of ten Central Human Capabilities (Nussbaum, 2003:36). Although this list is open to revision and must be further refined, Nussbaum argues that these ten capabilities are crucial and that based on them it can be determined whether a society can be said to be just (Ibid). According to Nussbaum, the list is the best way to secure 'fundamental rights' and it can enable the measurement and comparison of people's QoL (Nussbaum, 2003).

The ASCOT is a questionnaire with clearly demarcated domains. More specifically, the domains were defined by considering important goals of social care according to professionals, and which QoL aspects should be included to assess the effects of social care services received by older adults (Netten et al., 2011, Malley et al., 2012). The goals of social care were thus central in determining which domains should be included, and the perspective of older adults was not the starting point in determining the domains. To overcome this limitation, we conducted a review of studies on QoL from the perspective of older adults (Chapter 4), and we developed six extra domains based on the results of this review (Chapter 5). Combined with the ASCOT domains, this resulted in the EQLT, which encompasses many aspects of QoL that were shown to be important to older adults.

The resulting EQLT, therefore, did not focus specifically on domains that could be affected by social care. The purpose of the EQLT is not measuring and comparing outcomes between groups per se as is the goal of ASCOT, but to be used as a tool to identify important QoL domains given a certain context and based hereupon to guide a conversation about QoL to monitor these broader outcomes of care (Chapter 5).

How does the EQLT relate to the debate between Sen and Nussbaum? On the one hand, the definition of specific domains is in line with Nussbaum's approach of identifying core capabilities. On the other hand, our research focused on views and experiences of older people, and brought these together in a systematic way, resulting in the EQLT. This is more inclusive than Nussbaum's approach, which was theory driven (Zimmerman, 2006). Indeed, the methodology we used to identify these domains can be compared to the democratic process to select capabilities that was suggested by Sen, since we explicitly included the views of older people themselves, both in the systematic review (n=3,400 older adults) and in our interview study regarding the experienced influences of care services on QoL (Chapter 4).

We propose to extend this process of defining domains by involving older adults more actively, using a participatory research design (Abma & Broerse, 2010). In such a process, one should be careful about how to include various stakeholders. Who decides what domains or capabilities should be included? Some voices could dominate the conversation. How to establish a democratic process in which each voice is of equal weight?

Although a list of QoL domains limits the scope of what may be considered relevant by respondents, having clearly defined domains can be useful in order to compare QoL outcomes between groups and to evaluate care, which is the purpose of the ASCOT. A list of domains can also stimulate thinking and talking about QoL, which is the purpose of the EQLT (Chapter 5). For example, presenting a list of QoL domains to clients can help them in evaluating and reflecting upon what is important to them, and provides a starting point for reflection (Chapter 6).

Such a list, however, should not be used as an occasion for 'ticking the box', but rather as a starting point for a conversation about QoL. Or, in other words, as a tool that can contribute to sketching a narrative picture of important aspects in someone's life. These narratives can be used to inform decision making in care (Baldwin, 2015), and use of narratives are at the core of person-centered care (Villar & Serrat, 2017).

Health as a domain of quality of life?

In our studies, we showed that health is an important aspect of QoL. In Nussbaum's version of the CA, health is also defined as a Central Human Capability that is essential for flourishing (Nussbaum, 2003). Health can also influence other QoL domains (Van Leeuwen et al., 2019).

The ASCOT was developed to provide an alternative to preference-based QoL instruments focusing primarily on health, of which the EQ-5D is the most widely used instrument (The EuroQoL 1990; Herdman et al., 2011). In the ASCOT, health is not included, because in social care broader goals are relevant than health improvement, and health improvement might also be unachievable for some people, e.g. older adults (Netten et al., 2012). Rather, the goal of social care is to improve a range of daily life aspects and support everyday functioning which is reflected in the domains included in the ASCOT.

Although the developers of the ASCOT chose not to include health as a domain, several arguments in favor of the inclusion of health in an instrument measuring QoL of elderly people living at home can be provided. First, health is an important aspect of QoL according to older adults themselves (Milte et al., 2014; Tkatch et al., 2017; Halaweh et al., 2018; Van Leeuwen et al., 2019). Second, although overall health is often not substantially improvable in this context, as older adults may have multiple chronic conditions that cannot be cured, health care might still improve specific aspects of health (Chapter 4; De Carvalho, 2017). Although social care may not actually improve health, it can influence the way someone experiences health. For instance, participating in (physical) activities at a day care center (such as gymnastics, yoga or light household or gardening) might positively influence overall fitness and flexibility, or sleep at night, thereby improving subjective health (Chapter 4). This example also shows that care services may influence various domains of QoL, as was shown in Chapter 4, making the argument that health is not an aim of social care less strong. Based on these arguments, we decided to include health as a domain in the EQLT.

How concrete should the domains be? Comparing the ASCOT and the ICECAP-O

For measuring or evaluating QoL in older adults, other instruments are available next to the ASCOT. An alternative is the ICEpop CAPability measure for Older people (ICECAP-O) (Coast et al., 2008). Like the ASCOT, it is based conceptually on the capability approach. Theoretically, a major difference between the two instruments concerns the level of concreteness of the domains that are identified.

The ASCOT consists of eight rather specific and concrete domains: *control over daily life, personal cleanliness and comfort, food and drink, personal safety, social participation and involvement, occupation, accommodation cleanliness* and *comfort and dignity.* In the ICECAP-O, the domains are described in more abstract terms. The five domains of the ICECAP-O, which are phrased as capabilities in terms of 'being able to be' or 'can have' are *attachment* ('love and friendship), *security* (thinking about the future without concern), *role* (doing things that make you feel valued, *enjoyment* (enjoyment and pleasure), *control* (independence) (www.birmingham.ac.uk). In comparison, the ICECAP-O leaves more room for individual interpretation than the ASCOT.

The two questionnaires have been compared and it was found that both measures, to a certain degree, measured the same construct, but that there are also some differences regarding the specific domains. For example, the ICECAP-O item 'attachment' has a different meaning to respondents than the ASCOT item 'social participation and involvement' (Hackert et al., 2017). Moreover, the ASCOT measures specific social care–related outcomes that are not included in the ICECAP-O, which is in line with the aim and composition of the measure (Hackert et al., 2017). Among older adults, differences between ASCOT and ICECAP-O in reliability were small (van Leeuwen et al., 2015). Overall, research suggests that the ASCOT is more sensitive in measuring social care-related outcomes (Hackert et al., 2017) such as self-perceived QoL, mastery and client-centeredness of home care (van Leeuwen et al., 2015).

In the ASCOT, because of the fact that domains are more concretely specified, people are less able to decide for themselves which aspects of QoL are important to them or how they interpret certain Qol aspects in the context of their own daily lives, compared to the ICECAP-O. A disadvantage of this is that there is less room for personal aspects and cultural differences (although it facilitates measurements and comparisons). However, having a conversation about why someone has filled in certain answers could stimulate discussing a personal narrative. Discussing a narrative can improve care (Ubels, 2015). The concreteness of the questions can stimulate thinking and talking about these topics.

An advantage of ICECAP-O is, that people can articulate themselves what abstract concepts mean to them in their everyday life. This may positively influence demand-driven care, or person-centered care, i.e. care that is attentive to the personal, and perhaps unique, needs of people. However, also here a conversation about the individual interpretation of domains is required to ensure this personalization.

Overall, we conclude that, regardless of the level of abstractness or concreteness of the questions, it is important to check the meaning of the answer and have a conversation with the person about their view and experiences regarding QoL.

Caring for quality of life: some social justice considerations

Our philosophical analysis showed that the ASCOT, in line with the CA, focusses on autonomy and freedom of choice: the preferences, needs and opportunities of a person should be central in the provision of care and evaluation of its outcomes. Likewise, our empirical study in Chapter 4 showed that autonomy is crucial for older adults, and that care can affect autonomy, since not being able to make one's own choices has a negative impact on QoL (e.g. often having to wait for transport services can increase feelings of being dependent on others, and decrease feelings of dignity). Yet the question remains to what extent autonomy and freedom of choice should be promoted and supported in the provision of care to older adults living at home. How far should care providing organizations go in meeting individual care needs?

This question involves two issues. First, should care be personalized? How 'diversity responsive' should care be? What can we realistically offer with and expect from social care services if respect for autonomy and freedom of choice are leading values? Second, should the focus be on care professionals, or should care be provided in other ways, based on participation of groups in society?

Limitations of personalizing care goals

As discussed in Chapter 2, the ASCOT focuses on personal freedom and choice, recognizes that there is a diversity in wishes and needs, and puts the person central, which is in line with the CA. Perhaps even more than in curative health care, in the care services received at home (medical, social and support in daily living), individual choices are important. Care services at home influence everyday life, and what brings quality to this life can be perceived very differently from person to person. This is reflected in the element 'as I want' in the answer options to accommodate for personal choice.

In our thematic synthesis in Chapter 3, we found that QoL for older people living at home entails more aspects than presently accounted for in the ASCOT. Our study described in Chapter 4, an interview study about how care services contribute to QoL according to adults, showed that broad aspects of QoL are indeed relevant and should be included in the evaluation of these services. Therefore, we developed the EQLT which is presented in Chapter 5. We also found that the EQLT can be used in the context of a narrative approach, the relevant domains are first identified and subsequently used as guidance for conversation about QoL. In this way it is possible to focus on the way the client tells his or her life and corresponding caring needs, to understand better what is important to individual older adults and how care services may address this. Given differences in preferences and diversity in people, combined with many possibly important QoL outcomes, a question is to what extent social care should be personalized. How far should we go in distinguishing personal needs and wishes and taking autonomy into account when evaluating care (Dunn, 2018)?

Personalized care entails offering different kinds of activities, matching older adults' interests and identities (Dunn, 2018). The outcomes of personalized care, however, cannot easily be evaluated. First, individually determined (personalized) outcome goals can be difficult to measure and compare. If person A values other domains of QoL than person B, it is hard to compare the outcomes. How then to compare the quality of various care providers? In order to be able to compare the outcomes of different care providers or different care services a fixed set of domains, such as included in the ASCOT, is needed. This inevitably implies less personalization of care.

Second, barriers such as scarcity of resources and time might prevent personalization of care. Optimizing freedom and choice cannot be done endlessly. There is a tension between individual wishes and needs and taking care of many people; time and budget are limited. Resources available for health care are insufficient to meet all health care needs in a society (Daniels, 2010). The demand for care services is always higher than the supply (Buijsen, 2010). Budgets are limited and providing services to some, means declining access to others (Daniels, 2010). When distributing the scarce resources available for healthcare, policy makers aim to maximize benefits (Drummond, 2015; Johnston, 2004). Although focusing on capabilities is attractive, the CA does not provide a clear guidance for these distributional problems (Robeyns, 2006).

How can we use the CA to achieve a maximization of capabilities (Venkatapuram, 2011)? Should we first ensure a threshold level of basic capabilities, as Nussbaum suggests, or rather prioritize the maximization of the total capabilities of a population (ibid)? Enabling each citizen to achieve a minimum threshold level in these basic capabilities could mean spending a great amount of resources on the improvement of capabilities of one person above the sufficiency level, whilst more could be gained by fostering the capabilities of people who are already above the threshold level (Venkatapuram, 2011).

Beyond the professional-client dyad in formal care

The question of whether it is feasible to accommodate for personal needs and wishes is even more pressing in times of shrinking health care budgets and an increasing number of older adults in most Western societies (RIVM, 2020; CPB, 2020). Is the current system sustainable for the future? And should care services, or the government, be solely responsible for accommodating for the wishes of older adults living at home who need care? The current provision of care is based on the concept of the professional-client dyad, in which the professional caretaker provides care and the older adult receives this care in a passive way. Furthermore, the involvement of third parties in care is considered less. Here, we will explore some innovative ideas on realizing care for older adults that go beyond this concept of the professional-client dyad (Dunn, 2018).

Dunn argues for a shared ethical concern and responsibility for older adults' autonomy. Dunn acknowledges the importance of supporting older adults in their agency and their capabilities as much as possible (Dunn, 2018). Agency is the capacity of individuals to act independently and to make their own free choices (Emirbayer & Mische, 1998). Dunn maintains that, to safeguard autonomy, care should not be provided in a relationship of dependency, but as a partnership, in which older adults have a voice and a responsibility. Dunn argues that we should move towards a shared responsibility in caring for older adults, shifting away from a 'dependency-led approach, where the focus is on meeting the older person's needs, to a partnership model, where caregiver and care recipient are both participants engaged in a shared, social process of exercising their agency together or alongside each other' (Dunn, 2018: p. 29).

Additionally, Dunn maintains that we have a polarized view on who is responsible for care for older adults, as either the government or family (Dunn, 2018). He argues that meeting care and support needs of older adults is a joint responsibility; it is not solely the responsibility of the government. Dunn suggests training volunteers to act as partners in supporting older adults' agency, helping them for example in deciding what kind of social activities they should pursue, assisting them in these activities and making sure these activities remain aligned with personal values.

Alan Kellehear (2019) also pleads for a move beyond traditional government led care systems. In order to include society, Kellehear proposes specific programs that raise awareness of the 'need for every community member to become actively involved in the care of the frail and vulnerable in their own locality despite not necessarily 'knowing' these people' (2013: p. 1073). These programs could lead to the development of broader care networks, resulting in a reduction in crisis health care services and decreased feelings of loneliness and isolation by people receiving this support. Kellehear describes a project in Japan, where people living with dementia were actively involved in the preparation of their meal, doing groceries and producing their lunch. Shopkeepers were informed and participated in the program, communicated with these older adults and 'gained insight into the complexities of their care, while sharing this in a small way' (Kellehear, 2013: p. 1074). Drawing on such examples, Kellehear argues for developing 'compassionate cities', where caring for others is a shared responsibility of the community, not solely that of professional health and social services.

To evaluate and compare the outcomes of these projects, the ASCOT can be used to understand how these initiatives contribute to older adults' QoL. Besides increasing autonomy or dignity, this new organization of compassionate care could increase feelings of personal safety or social participation and involvement. Additionally, the EQLT with its additional domains could be a useful tool in conversation between caretakers and providers to help them focus on what is important. Using this tool is not limited to professional caretakers, but can also be done by informal caretakers, such as family members, neighbors and volunteers.

Thinking about the future of care for older adults living at home, we should reconsider existing structures and ways of organizing care. In societies with increasing populations of older adults, and decreasing health care budgets, care needs to be organized differently. Responsibilities in care require renegotiation, while including third parties (volunteers, community members) and older adults themselves. The experience of autonomy in older adults should be leading in this reconsideration. Finally, we should not see older adults as 'others', i.e. as a group separated from society. Most of us will become an older adult, so the leading question should be: How would *we* wish to be cared for?

Strengths and limitations

The studies described in this thesis have several strengths and limitations. First, an overall strength of this thesis is the multidisciplinary approach; philosophical analysis and empirical research into views and experiences of older people are combined to gain better insight in understanding QoL in older adults. Combining different approaches and methodologies provides a better understanding of a complex issue like QoL and serve as a basis for (normative) conclusions.

Second, a strength is the way in which we addressed the content validity of the ASCOT. According to the COSMIN guideline the theoretical grounds - if any - of a questionnaire should be clear (Terwee et al., 2018). Here, philosophical analysis helped to make explicit relevant underlying theoretical foundations of the ASCOT. Also, empirical research into views of older adults and other stakeholders contributed to the validation of the ASCOT domains.

A third strength of this thesis is the way in which we investigated the perspective of older adults themselves on QoL and the relevance of care services. We did a comprehensive study of in total the views of 3,400 older adults on what QoL means to them, and also a study on views of older adults concerning the contribution of care services to QoL. The tool we developed based on the findings of these studies, the EQLT, can help to put their perspectives, including the capabilities they find important, central in the actual care they receive.

A first limitation of this thesis is that it presents only a part of our larger project on the ASCOT-NL. Because of the interdisciplinary character of the ASCOT-NL project, not all studies were included in the current thesis. Aspects that have been studied in the ASCOT-NL project that are not discussed in this thesis are: 1) a study on the Dutch preferences weights for the ASCOT-NL, 2) a report on the development of the EQLT.

A second limitation is that this thesis focuses on formal care. However, older adults often also receive informal care – by family members, neighbors, volunteers, etc. The amount and quality of informal care they receive vary to a great extent among individuals, but may have an important influence on their QoL. The way in which and the extent to which the effects of informal care interact with those of formal care services on QoL remains unexplored in this thesis. Nonetheless, in the discussion, we argue that society should move towards a shared responsibility in caring for older adults, emphasizing the importance of combining informal with formal care.

A third limitation regards the lack of active involvement of stakeholders in the development of the EQLT. Older persons and other stakeholders were merely respondents in this study, and did not actively contribute to the outcomes in a participatory way.

Recommendations

In this final paragraph, we present recommendations that follow from the main conclusions of this thesis regarding further research, implementation and organization of care for older adults living at home.

Research

The main recommendation regarding research is to investigate the use of the EQLT as a communication tool. We propose to use the EQLT to identify the relevant domains in a given context and to subsequently develop a narrative of QoL, that is to enable caregivers to have a conversation with older adults about what is important to their QoL. Such a conversation should allow caregivers and older adults to go beyond 'ticking a box'. However, research needs to be done into the validity of the EQLT and its additional domains. Research on the actual implementation of the EQLT as strategy to identify relevant domains to enable to start a conversation may clarify how to balance between using a structured list of domains and focusing on someone's personal QoL narrative.

The flexibility of the EQLT allows for tailoring it to individual needs, since there are differences between different people, but also within individuals over time regarding what is relevant in terms of QoL. A pilot study in which the EQLT is implemented in daily practice can provide information to further understand possible barriers and facilitators for implementation and use in practice; how should the instrument be used? How to train people to use it?

Participatory research methods, including older adults and other stakeholders, can be used to further determine which aspects of QoL are relevant in different settings, while also focusing on cultural differences in perspective on QoL. This can lead to new insights into diversity aspects of QoL and provide a basis for co-creation of new tools by fostering cooperation between researchers, caregivers and older adults.

Implementation

The evaluation of outcomes of care services in older adults living at home should be based on an instrument that covers a wide range of QoL domains. We propose to use the ASCOT as an instrument for economic evaluation, measuring QoL in older adults at home as an outcome of care services in the Netherlands. The ASCOT offers a broader focus on QoL outcomes than commonly used QoL instruments such as the EQ-5D-5L. Furthermore, the ASCOT offers an opportunity to compare outcomes of different service providers. This allows for comparing groups, comparing organizations, and comparing individuals over time. The EQLT can be used to set individual goals of care in certain contexts, to develop a personal narrative, and to monitor QoL over time. Care organizations could use the EQLT to make decisions about provision of care.

Organization of care

Further adjustment of services to individual preferences or needs is recommended to increase the experience of autonomy in older adults, as this experience is found to be important to QoL. The freedom to choose what is important for QoL should be central in the provision of care for older adults living at home.

Furthermore, to meet the challenges of an ageing population in the long run, the broader community should be included in care for older adults at home, as caring for the capabilities of older adults should be seen as a joint responsibility, rather than a responsibility that should be primarily delegated to formal services.

Conclusions

There is a need for a broad QoL tool to evaluate care in older adults living at home. The ASCOT is such a tool. It operationalizes the core assumptions of the capability approach, translating this approach in a practical instrument. From the point of view of older adults, some important domains are missing in the ASCOT. These domains have been included in an extension of the ASCOT, i.e. the EQLT. The domains identified in the EQLT should not be used as tick boxes, but should serve as issues to be discussed in a conversation between clients and care providers. In this way, the perspective of older adults on their QoL can be a guiding principle in the care they receive, in a way that maximizes the influence of care on their capabilities.

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APPENDICES

Summary
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Summary

The central aim of this thesis is to gain a better understanding about what is important for the quality of life (QoL) of older adults living at home receiving professional care services, and how to assess outcomes of this care in terms of QoL. Specifically, this thesis focuses on how the Adult Social Care Outcomes Toolkit (ASCOT) can be used for determining QoL of older adults in the Netherlands. The ASCOT is an instrument developed in the UK that was designed to evaluate outcomes of social care services by capturing information about an individual's QoL in eight domains: control over daily life, personal cleanliness and comfort, food and drink, personal safety, social participation and involvement, occupation, accommodation cleanliness and comfort and dignity. The ASCOT is inspired by the Capability Approach (CA). In CA, a distinction is made between capabilities - the things a person has, and functionings - the things a person does. When someone has a capability, they can choose to use it or not. Someone who has access to food can choose to eat but can also consciously refrain from eating, for example in the case of a hunger strike. Central to this are both having access to possibilities, and the freedom to use them or not.

In the introduction (Chapter 1), the context aim of the thesis are introduced. Older adults increasingly live at home and, in this setting, may be confronted with difficulties in their daily life affecting their QoL, for instance a decrease in mobility. The opportunities to engage in various activities and autonomy, i.e. control over one's life, often decrease because of these difficulties. Care services can support older adults in dealing with challenges and maintaining a preferred level of functioning, contributing to their QoL. The ASCOT is introduced as an instrument to measure outcomes of care for older adults living at home, focusing on the perspective of the care receiver.

In Chapter 1, four questions are formulated that are the focus of this thesis: 1) How can the ASCOT be understood from the philosophical perspective of the CA? 2) What are important aspects of QoL from the perspective of older adults living at home? 3) How can care services contribute to QoL in older adults living at home? 4) How can important aspects of QoL from the perspective of older adults living at home be addressed in QoL instruments? Within this thesis, different methodologies are combined to answer these questions, in line with and inspired by an empirical ethics approach. In this way, the question how to define QoL in older adults is explored drawing on the strengths of both philosophical and empirical analysis.

Chapter 2 presents a philosophical analysis of the relationship between the Capability Approach (CA) and the ASCOT is presented. The ASCOT is inspired by the CA. In the CA, capabilities are crucial for QoL. More specifically, the focus of the CA is not on what people actually do, but what they can choose to do and pursue, based on what they regard as meaningful and valuable.

Three main characteristics of the CA are discussed and related to the

evaluation of QoL in older adults. First, the focus of QoL evaluation should not be on functioning, but on freedom of choice. People should have the ability to choose certain functionings; people are diverse and value opportunities differently; and people have different opportunities to convert resources into capabilities. We should therefore evaluate capabilities, meaning we should evaluate whether people are able to do what they would like to be able to do. Second, evaluation of QoL should take into account the downside of so-called 'adaptive preferences', i.e. that preferences may change as people lower their expectations in situations of limited possibilities. This is important, because this does not mean that their situation cannot or should not be improved. Third, evaluation of QoL should not only address health, but also other domains of life.

On the basis of this analysis, it is argued that the ASCOT can be regarded as an operationalization of the CA. Our analysis demonstrated that freedom of choice is adequately reflected in the response option 'as I want' in the ASCOT questionnaire. The problem of adaptive preferences is countered in the ASCOT by developing a standard based on preferences of the general population. Third, the ASCOT contains a broader perspective on QoL, thus going beyond only evaluating health.

Chapter 3 presents a thematic synthesis review of the meaning of QoL for older adults. This study provides a systematic overview of what older adults themselves find important, providing the possibility to align goals of services with the aspects of QoL important to older adults.

In order to assemble a more comprehensive picture of QoL, the empirical findings from multiple qualitative studies were combined in a synthesis providing a range and depth of meanings, experiences, and perspectives of participants across contexts. Data from 48 qualitative studies representing the views of more than 3,400 older adults living at home in 11 Western countries were analyzed to distinguish different aspects of QoL, resulting in the identification of nine domains: autonomy, role and activity, health perception, relationships, attitude and adaptation, emotional comfort, spirituality, home and neighborhood, and financial security. The outcomes show that different domains are strongly connected and overlap; QoL should be seen as a dynamic web of intertwined domains.

In Chapter 4, the results of an empirical study exploring the experiences of older people living at home receiving different care services are presented. More specifically, we describe how older people living at home viewed the contribution to their QoL of three types of care services – medical services, social support services and support in daily living. The ASCOT domains and domains found in the thematic review are used as a theoretical framework.

The study showed that for older persons living at home, medical services, social care services and services that support daily living impact a broad range of QoL domains. Medical services were found not only to restore physical health, but also to provide support in maintaining an adequate level of functioning and they support older adults to cope with their situation. Social care services and services that support daily living were found to play an important role in QOL especially in fostering autonomy and maintaining relationships.

Overall, improving autonomy was seen as the most important goal of care by older adults living at home. When evaluating the outcomes of care services possible adverse effects should also be taken into account. Another important finding of this study is that older adults living at home are supported by services in ways that go beyond the core tasks of professionals. Respondents valued extra activities e.g. having a cup of coffee and having a chat with caretakers.

Chapter 5 focuses on the relevance of the findings from the previous chapters for Dutch care practice. First, the Dutch version of the ASCOT, the ASCOT-NL, is presented. Next, we propose a quality tool, based on the ASCOT, with additions based on the results of the thematic synthesis (Chapter 3). This tool is called the Extended Quality of Life Tool (EQLT). Additional domains in the EQLT, not included in the ASCOT, are: accessibility and age-friendliness of the neighborhood; connectedness; financial security; perceived health; resilience and emotional comfort. The EQLT consists in total of 14 domains: the 6 additional domains in combination with the 8 ASCOT domains. The EQLT can help to understand a wide range of capabilities that are important to older adults in terms of QoL. Whereas the ASCOT can be used to evaluate care services, the EQLT can be used as guidance during conversations with older adults about domains of QoL that matter to them, and that could be targeted by care services.

Chapter 6, investigates the views of stakeholders on the relevance of the EQLT for practice, as well as facilitators and barriers for implementation. Stakeholders considered four characteristics of the tool as relevant: the focus on the client perspective; the perspective on Quality of Life which is broader than health alone; the possibility to take diversity into account; and the possibility to determine a minimum level of QoL as a standard. Furthermore, three facilitators for implementation were found: the tool is attractive as it can be used as guidance for conversation with the clients; it can be used in a flexible way; and it provides organizations an opportunity to learn from each other's outcomes. Finally, four barriers were identified: the tool may distract attention of the health care professionals from their core activities; there may be a lack of time to implement the instrument; the health care professionals may have resistance to measurement tools results may not be useful because of an absence of adequate funding.

The results underline the relevance of the EQLT, as it has the potential to support dialogues between caregivers and clients about their needs and wishes based on a broad set of domains of QoL. This provides a basis for personalized care, i.e. care in which people have choice and control over the way their care is planned and delivered.

In Chapter 7, the main findings of this thesis are discussed. Also, two challenges in measuring the effects of interventions in care in older adults living at home are addressed: (1) how to do justice to the diverse experience of QoL and (2) how to combine caring for QoL and social justice.

The first challenge concerns the question of using a standard domains in a QoL instrument. A set of standard domains may not do justice to diversity amongst older adults, taking into account their individual wishes and needs.

Within the CA, there is a similar discussion about using a list of pre-fixed capabilities. Whereas Nussbaum argues we need a list in order to set a minimum QoL standard for everyone, Sen argues that relevant capabilities should be selected through a democratic process. In line with Sen, we argue that empirical research, as provided in this thesis, can be used to include the perspective of stakeholders in defining QoL domains.

The second challenge concerns issues of social justice. How far should care providing organizations go in meeting individual care needs? A tension is identified between taking into account individual wishes and needs and a just distribution of scarce resources over the population. Intrinsically related to this is the question who is – or should be – responsible for care for older adults. It is argued that we should not hold the government alone responsible. Rather, when thinking about the future of care for older adults living at home, we should reconsider existing structures, in health care as well as in society at large, and. Responsibilities in care could be renegotiated, including the responsibilities of third parties (volunteers, community members) and that of older adults themselves.

We conclude that there is a need for a broad QoL tool to evaluate care in older adults living at home. The ASCOT is such a tool. It operationalizes the core assumptions of the capability approach, translating this approach in a practical instrument. From the point of view of older adults, some important domains are missing in the ASCOT. These domains have been included in an extension of the ASCOT, i.e. the EQLT. The domains identified in the EQLT should not be used as tick boxes, but should serve as issues to be discussed in a conversation between clients and care providers. Further implementation of the ASCOT and the EQLT is recommended, not only in professional care, but also in informal care in the community.

Samenvatting

Het doel van dit proefschrift is om inzicht te krijgen in wat belangrijk is voor kwaliteit van leven (KvL) van thuiswonende ouderen die professionele zorg ontvangen en hoe uitkomsten van deze zorg kunnen worden beoordeeld in termen van KvL. Deze thesis richt zich specifiek op de manier waarop de Adult Social Care Outcomes Toolkit (ASCOT) gebruikt kan worden voor het bepalen van de KvL van thuiswonende ouderen in Nederland. De ASCOT is ontwikkeld in het Verenigd Koninkrijk als instrument om uitkomsten van sociale zorgdiensten te evalueren. Dit gebeurt door iemands KvL te evalueren in acht domeinen: regie over het dagelijks leven; persoonlijke verzorging; eten en drinken; persoonlijke veiligheid; sociale participatie; tijdsbesteding; verzorgde woning en comfort; waardigheid. De ASCOT is geïnspireerd door de Capability Approach (CA). In de CA wordt een onderscheid gemaakt tussen capabilities – de mogelijkheden die iemand heeft, en functionings – de dingen die iemand doet. Wanneer iemand over een mogelijkheid beschikt, kan hij ervoor kiezen deze al dan niet te gebruiken. Iemand die toegang heeft tot voedsel, kan ervoor kiezen te eten maar kan ook bewust afzien van eten, bijvoorbeeld in geval van hongerstaking. Centraal staan zowel de beschikking hebben over mogelijkheden, als de vrijheid deze al dan niet te gebruiken.

In de inleiding (Hoofdstuk 1) worden de context en het doel van het proefschrift geïntroduceerd. Ouderen wonen steeds vaker thuis en kunnen in deze omgeving geconfronteerd worden met moeilijkheden in hun dagelijks leven die hun KvL beïnvloeden, bijvoorbeeld een afname van mobiliteit. De mogelijkheden om deel te nemen aan verschillende activiteiten en autonomie, d.w.z. de controle over hun leven, nemen vaak af door deze moeilijkheden. Zorgdiensten kunnen ouderen ondersteunen bij het omgaan met uitdagingen en het behouden van een gewenst niveau van functioneren, wat bijdraagt aan hun KvL. De ASCOT wordt geïntroduceerd als instrument om de uitkomsten van de zorg voor thuiswonende ouderen te meten, met de nadruk op het perspectief van de zorgontvanger.

In Hoofdstuk 1 worden vier vragen geformuleerd die in deze thesis centraal staan: 1) Hoe kan de ASCOT begrepen worden vanuit het filosofisch perspectief van de CA? 2) Wat zijn belangrijke aspecten van KvL vanuit het perspectief van thuiswonende ouderen? 3) Hoe kunnen zorgdiensten bijdragen aan KvL bij thuiswonende ouderen? 4) Hoe kunnen belangrijke aspecten van KvL vanuit het perspectief van thuiswonende ouderen worden geïncorporeerd in KvL-instrumenten? Binnen deze thesis zijn verschillende methodologieën gecombineerd om deze vragen te beantwoorden, in lijn met, en geïnspireerd door, een empirisch-ethische benadering. Op deze manier wordt de vraag onderzocht hoe KvL bij ouderen gedefinieerd kan worden, waarbij de sterke punten van zowel filosofische als empirische analyses gecombineerd worden.

Hoofdstuk 2 is een filosofische analyse van de relatie tussen de Capability Approach (CA) en de ASCOT gepresenteerd. De ASCOT is geïnspireerd door de CA.

In de CA zijn capabilities cruciaal voor KvL. Meer specifiek ligt de focus van de CA niet op wat mensen feitelijk doen, maar op wat ze kunnen kiezen om te doen en na te streven, gebaseerd op wat ze zinvol en/of waardevol vinden.

Drie belangrijke kenmerken van de CA worden besproken en in verband gebracht met de evaluatie van KvL bij ouderen. Ten eerste moet de nadruk bij de evaluatie van KvL niet liggen op functioneren, maar op keuzevrijheid. Mensen moeten mogelijkheid hebben om bepaalde functies te kiezen; mensen zijn divers en waarderen mogelijkheden verschillend; en mensen hebben verschillende mogelijkheden om middelen om te zetten in capabilities. Daarom moeten de capabilities worden geëvalueerd. Met andere woorden, er moet worden geëvalueerd of mensen in staat zijn te doen wat zij graag zouden willen en kunnen doen. Ten tweede moet bij de evaluatie van KvL rekening worden gehouden met de keerzijde van de zogenaamde "adaptieve voorkeuren" (adaptive preferences), d.w.z. dat mensen hun verwachtingen verlagen in omstandigheden van beperkte mogelijkheden. Dit is belangrijk, omdat dit niet betekent dat hun situatie niet kan of moet worden verbeterd. Ten derde moet de evaluatie van KvL niet alleen betrekking hebben op de gezondheid, maar ook op andere levensdomeinen.

Op basis van deze analyse wordt beargumenteerd dat de ASCOT kan worden beschouwd als een operationalisering van de CA. Onze analyse toont aan dat keuzevrijheid adequaat wordt weerspiegeld in de antwoordmogelijkheid "zoals ik wil" in de ASCOT-vragenlijst. De ASCOT houdt rekening met adaptieve voorkeuren door een standaard te ontwikkelen die gebaseerd is op voorkeuren van de algemene bevolking. Ten derde bevat de ASCOT verschillende domeinen van KvL, en hanteert daarmee een breder perspectief op KvL dan alleen het evalueren van gezondheid.

Hoofdstuk 3 presenteert een systematische literatuurstudie naar de betekenis van KvL voor thuiswonende ouderen. Deze studie geeft een systematisch overzicht van wat ouderen zelf belangrijk vinden, en biedt daarmee de mogelijkheid om doelen van diensten af te stemmen op die aspecten van KvL die voor ouderen zelf belangrijk zijn.

Voor het verkrijgen van een breed beeld van KvL, worden empirische bevindingen van meerdere kwalitatieve studies gecombineerd in een synthese die een breed scala aan betekenissen, ervaringen en perspectieven van deelnemers in verschillende contexten beschrijft.. Gegevens van 48 kwalitatieve studies die de ervaringen van meer dan 3.400 thuiswonende ouderen in 11 Westerse landen vertegenwoordigen, worden geanalyseerd om verschillende aspecten van KvL te onderscheiden. Dit resulteert in de identificatie van negen domeinen: autonomie, rol en tijdsbesteding, gezondheid, relaties, attitude en aanpassingsvermogen, emotioneel comfort, spiritualiteit, huis en omgeving, en financiële zekerheid. De uitkomsten laten zien dat de verschillende domeinen sterk met elkaar verbonden zijn en overlappen; KvL moet worden gezien als een dynamisch web van met elkaar verweven domeinen.

In Hoofdstuk 4 worden de resultaten gepresenteerd van een empirisch onderzoek naar ervaringen van thuiswonende ouderen die verschillende zorgdiensten ontvangen. We beschrijven hoe thuiswonende ouderen de bijdrage van drie soorten zorgverlening - medische zorg, sociale zorg en ondersteuning bij het dagelijks leven - aan hun kwaliteit van leven ervaren. De ASCOT-domeinen en de domeinen uit de systematische literatuurstudie worden gebruikt als theoretisch kader.

De studie toont aan dat voor thuiswonende ouderen medische diensten, sociale zorgdiensten en diensten ter ondersteuning van het dagelijks leven een breed scala aan KvL domeinen beïnvloeden. Medische diensten blijken niet alleen de fysieke gezondheid te herstellen, maar ook ondersteuning te bieden bij het behouden van een adequaat niveau van functioneren. Daarnaast ondersteunen medische diensten de ouderen om beter met hun situatie om te kunnen gaan. Sociale zorg en diensten ter ondersteuning van het dagelijks leven blijken een belangrijke rol te spelen bij de KvL, vooral bij het bevorderen van autonomie en het onderhouden van relaties.

Over het algemeen wordt het verbeteren van de autonomie door thuiswonende ouderen gezien als het belangrijkste doel van zorg. Bij de evaluatie van de resultaten van zorgdiensten moet ook rekening worden gehouden met mogelijke negatieve effecten, zoals de vermindering van autonomie door gevoelens van afhankelijkheid. Een andere belangrijke bevinding van deze studie is dat thuiswonende ouderen door zorgprofessionals ondersteund worden op gebieden die verder gaan dan de kerntaak van de zorgprofessional. De respondenten waardeerden extra activiteiten, zoals het drinken van een kopje koffie en een praatje maken met verzorgers.

Hoofdstuk 5 richt zich op de relevantie van de bevindingen uit de voorgaande hoofdstukken voor de Nederlandse zorgpraktijk. Eerst wordt de Nederlandse versie van de ASCOT, de ASCOT-NL, gepresenteerd. Vervolgens presenteren we een kwaliteitsinstrument dat gebaseerd is op de ASCOT, met aanvullingen op basis van de resultaten van de systematische literatuuranalyse (Hoofdstuk 3). Dit instrument wordt de Extended Quality of Life Tool (EQLT) genoemd. Extra domeinen in deze EQLT die niet in de ASCOT zijn opgenomen zijn: toegankelijkheid en leeftijdsvriendelijkheid van de buurt; verbondenheid; financiële zekerheid; waargenomen gezondheid; veerkracht en emotioneel comfort. Daarmee bestaat de EQLT in totaal uit 14 domeinen: de 6 toegevoegde domeinen in combinatie met de 8 ASCOT domeinen. De EQLT kan helpen om inzicht te krijgen in een breed scala aan capabilities die voor ouderen belangrijk zijn in termen van KvL. Terwijl de ASCOT gebruikt kan worden om zorgdiensten te evalueren, kan de EQLT gebruikt worden als leidraad tijdens gesprekken met ouderen over domeinen van KvL die voor hen van belang zijn, en waarop zorgdiensten zich zouden kunnen richten.

Hoofdstuk 6 onderzoekt de ideeën van betrokken stakeholders over de relevantie van de EQLT voor de praktijk, en over mogelijke bevorderende en belemmerende factoren voor implementatie. De stakeholders beschouwen vier kenmerken van het instrument als relevant: de focus op het cliëntenperspectief; het perspectief op kwaliteit van leven als meer dan gezondheid alleen; de mogelijkheid om rekening te houden met diversiteit; en de mogelijkheid om een minimumniveau van kwaliteit van leven als norm te hanteren.

Verder worden drie bevorderende factoren voor de implementatie gevonden: het instrument is aantrekkelijk omdat het kan worden gebruikt als leidraad voor een gesprek met cliënten; het kan op een flexibele manier worden gebruikt; en het biedt organisaties de mogelijkheid om van elkaars uitkomsten te leren. Ten slotte worden vier barrières geïdentificeerd: het instrument kan de aandacht van de zorgverleners afleiden van hun kernactiviteiten; de tijd kan ontbreken om het instrument toe te passen; zorgverleners kunnen weerstand hebben t.a.v. het gebruik van meetinstrumenten; de resultaten van metingen kunnen niet bruikbaar zijn door een gebrek aan adequate financiering.

De resultaten onderstrepen de relevantie van de EQLT, omdat deze het potentieel heeft om dialogen tussen zorgverleners en cliënten over hun behoeften en wensen op basis van een brede set van domeinen van KvL te ondersteunen. Dit biedt een basis voor gepersonaliseerde zorg, d.w.z. zorg waarbij mensen keuze en controle hebben over de manier waarop hun zorg wordt gepland en geleverd.

In Hoofdstuk 7 worden de belangrijkste bevindingen van dit proefschrift besproken. Ook wordt ingegaan op twee uitdagingen bij het meten van de effecten van interventies in de zorg bij thuiswonende ouderen: (1) hoe recht te doen aan diversiteit in de beleving van KvL en (2) hoe de zorg voor KvL en sociale rechtvaardigheid te combineren.

De eerste uitdaging betreft de vraag of het gebruik van standaarddomeinen in een KvL-instrument recht doet aan de diversiteit onder ouderen, rekening houdend met hun individuele wensen en behoeften. Binnen de CA is er een vergelijkbare discussie over het gebruik van een lijst van vooraf vastgelegde capabilities. Waar Nussbaum stelt dat we een lijst nodig hebben om voor iedereen een minimum KvL-norm vast te stellen, stelt Sen dat relevante capabilities via een democratisch proces moeten worden vastgesteld. In lijn met Sen stellen wij dat empirisch onderzoek, zoals in dit proefschrift, gebruikt kan worden om het perspectief van stakeholders te betrekken bij het definiëren van KvL domeinen.

De tweede uitdaging betreft kwesties van sociale rechtvaardigheid. Hoe ver moeten zorgorganisaties gaan in het beantwoorden van individuele zorgbehoeften? Er is een spanningsveld tussen het rekening houden met individuele wensen en behoeften en een rechtvaardige verdeling van schaarse middelen over de bevolking. Intrinsiek hiermee verbonden is de vraag wie verantwoordelijk is - of zou moeten zijn - voor de zorg voor ouderen. Er wordt betoogd dat we niet alleen de overheid verantwoordelijk moeten stellen. Als we nadenken over de toekomst van de zorg voor thuiswonende ouderen, moeten we de bestaande structuren, zowel in de gezondheidszorg als in de samenleving in het algemeen, opnieuw bekijken en de verantwoordelijkheden van derden (vrijwilligers, leden van de gemeenschap) en die van de ouderen zelf in de beschouwing betrekken.

We concluderen dat er behoefte is aan een breder KvL instrument om doelen in de zorg voor ouderen te bepalen en een gesprek over KvL mogelijk te maken. De ASCOT is zo'n instrument. De ASCOT biedt een operationalisering van de centrale uitgangspunten van de CA. Vanuit het oogpunt van oudere volwassenen ontbreken enkele belangrijke domeinen in de ASCOT. Deze domeinen zijn opgenomen in de EQLT. De EQLT kan worden gebruikt om zorgdoelen te definiëren die zijn gericht op de behoeften en wensen van de zorgontvanger. De domeinen die zijn geïdentificeerd in de ASCOT en de EQLT mogen niet worden gebruikt als vakjes om aan te kruisen, maar moeten gezien worden als onderwerpen voor een gesprek tussen cliënten en zorgverleners (d.w.z. gedeelde besluitvorming). Verdere implementatie van de ASCOT en de EQLT wordt aanbevolen, niet alleen in de professionele zorg, maar ook in de informele zorg in de samenleving.

LIST OF PUBLICATIONS

Van Loon, M., Van Leeuwen, K. M., Metselaar, S. Ostelo, R. W. J. G., Bosmans, J. E., & Widdershoven, G. A. M. How do care services contribute to quality of life? Views and experiences of Dutch older adults living at home. *Resubmitted after revisions*

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