



Peterjan van der Wal

# Wat maakt het leven de moeite waard?

Ouderen aan het woord die permanent van intensieve zorg afhankelijk zijn

Boekencentrum Academic



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**What makes life worth living?**  
Perspectives of elderly people dependent on permanent care  
(with a Summary in English)

**Was macht das Leben lebenswert?**  
Perspektiven älterer pflegebedürftiger Menschen  
(mit einer Zusammenfassung in deutscher Sprache)

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# Summary

"Every stage of life has its own characteristics and its own charm" (Cicero)

Never before in the history of our country have so many people become so old under such fortunate circumstances. At the same time, the ambivalence is great: people want to grow old without feeling old. At the beginning of the 21st century, the active and vital senior has become the role model and standard. It is generally preferred to ignore or repress the idea that less vital elderly people exist as well. When it comes to elderly people, only the vital elderly generally come to mind. We therefore differentiate between the care needs of three categories of elderly people: vital seniors, frail older persons who are at the pivot point between vital and dependent, and the dependent elderly who have lost control over their own lives to a greater or lesser degree and have become dependent on permanent care.

Can life in dependence on permanent care be worth living? This question is generally answered negatively or simply not asked at all, rather on the basis of sentiments than of knowledge or experience. The elderly themselves are hardly ever asked to voice their opinions. Quantitative empirical research recently carried out among somatic nursing home residents shows that the majority is satisfied with their lives and feel happy. Comparable figures concerning psycho-geriatric residents and elderly people dependent on permanent care at home are lacking until now.

This is the background against which this thesis has been written. The research question which we formulate and explain in Chapter 1 is as follows: *What makes life worth living for elderly people who are dependent on permanent care?* Step by step we try to gain insight into what makes the lives of these elderly people worth living and in what way and to what extent they are able to live their lives and experience them – against the general expectation – as valuable.

An exploration of literature in the field of (social) gerontology in chapter 2 shows that in scientific research there is little and fragmentary interest for care dependent elderly people and what gives value to their lives. Elderly people that are dependent on permanent care are almost completely invisible, both to the public eye and in academic research. At the end of a narrative review of our exploration it turns out that the research domains Quality of Life, Well-being, Meaning in Life and Spirituality can play a role in answering the question of what is of value to people, whereas they can hardly be found in most empirical studies. All these domains appear to be interconnected in a complex whole. Within the various areas of interest factors like personal circumstances, preferences and (life) orientation nowadays seem to play a particularly important role. In the end, meaning and what is significant turns out to be a complex phenomenon altogether.

As far as there is any knowledge about it, elderly people themselves appear to take a differentiated view of their own quality of life and even under difficult circumstances they are

generally able to maintain a sense of dignity and to maintain a meaningful life. The experts, however, for a long time seem to pay more attention to illness, disability and deterioration than to positive qualities and opportunities for growth: balance, well-being, feeling at home (even in nursing homes), satisfaction with life, spiritual wealth and growth. The expert's view on health is changing gradually.

On the basis of qualitative-empirical research we depict the experiences and opinions of a number of elderly people who are dependent on permanent care – which can be offered at home, as well as in the form of daycare or in the nursing home. What makes life worth living for them? We do this research in the form of a diptych.

In chapter 3, thirteen elderly people who depend on permanent somatic care are introduced on the basis of a semi-structured interview: five men and eight women of an average age of more than 83. From these interviews six predominant themes become apparent, namely: 1) connectedness, 2) doing something, 3) inner strength, 4) philosophy of life, 5) experienced health, and 6) housing and living conditions in the nursing home.

In chapter 4, elderly people who depend on permanent psycho-geriatric care are introduced in seven focus groups (two of people with early-stage dementia, two with informal caregivers, two with formal caregivers, one with residents of a psycho-geriatric ward) and two master classes (of health care professionals). This study accounts for a total of 75 participants, including 30 people with dementia: 22 women and 8 men with an average age of more than 80. The following six themes appear to be predominant: 1) connectedness, 2) autonomy, 3) equality, 4) role retention, 5) experienced health and 6) philosophy of life. In addition, people try to hold on to a meaningful life (meaning-based coping) in the form of a) staying busy doing what they still can do, b) keeping up with the struggle and c) lowering their goals.

The strong wish to remain connected is most prominent, with reciprocity and a sense of equality as important elements, also beneficial to being able to experience autonomy. The elderly people we investigated want to be able to play a meaningful role until the end of their lives. Their social network appears larger, closer and more diverse than is often thought. Specifically for people with early-stage dementia, contact with fellow-sufferers means a lot. Memories have a strikingly important function as a 'living relationship'. Another very important theme is having something to do: from pure passion to mere pastime, every pastime has both its own value and at the same time different significances for different people. Whereby passion adds most to the perceived quality of life, enjoying being able to do something for someone else unexpectedly and strikingly comes forward. Furthermore, reminiscing a pleasure is equally important as enjoying the actual moment and rest is just as natural and necessary as activity. Inner strength appears to be essential to endure a life dependent on permanent care. Religious faith turns out to play an important role for our respondents as a source of power in difficult circumstances, personal prayer is the most practiced ritual. Church attendance tends to increase in the nursing home compared to the situation at home, under the influence of the difficult circumstances and the possibilities offered in the home (within easy reach) and is particularly appreciated for the contacts with other visitors. Finding meaningful ways to deal with dependence on care becomes more important as one becomes increasingly dependent. All in all, the elderly people we interviewed clearly seem more vital and resilient *with respect to their sense of meaning* than older people in general,

according to Westerhof & Kuin (2007. Persoonlijke zingeving en ouderen: Een overzicht van theorie, empirie en praktijk. [Personal Meaning and the Elderly: An Overview of Theory, Empirics and Practice]. *Psyche en Geloof* 18(3), 118-135).

In chapter 5 following the doctoral research by Els van Wijngaarden (2016. *READY TO GIVE UP ON LIFE. A study into the lived experience of older people who consider their lives to be completed and no longer worth living.* Utrecht: Universiteit voor Humanistiek), we get acquainted with the lived experience of older people for whom life is no longer worth living (often referred to in The Netherlands as 'life completed'). They cannot, or do not want to, connect with their own lives anymore, whereas our discussion partners have not lost the thread of life, despite the circumstances they are living with). *In extremis* it concerns: 1) connectedness versus existential loneliness, 2) meaning until the end versus end without significance, 3) doing something versus doing nothing anymore and 4) resilience versus weariness of life.

The elderly people investigated by Van Wijngaarden cannot or do not want to accept their loss or the changes in their lives. In contrast, almost all of our respondents are able to overcome their struggles (which are nevertheless very real struggles) and to find and keep a new balance in their lives. The only way they are able to do so is by acknowledging and accepting the changed circumstances of their lives, and by letting go of fears. This is no easy task to complete, but nevertheless gives our respondents a perspective toward the future. This perspective entails discovering that against hardships (post-traumatic stress), new ways can be found to experience well-being and personal growth (post-traumatic growth). In the meaning-making of life, being connected to others is pivotal. In the research conducted by Van Wijngaarden, the elderly mostly seem to crave personal well-being and personal growth, which is what they fail to attain. In this way, Van Wijngaarden's research seems to portray a participant group of elderly people who miss out on positive experiences due to strong feelings of fear and loathing (connected to the unknown, vulnerability, the possibility of suffering and the possibility of an 'undignified' death). In addition, inability to cope with setbacks leaves these elderly more prone to depression. Their self esteem seems merely based on what they do and to a lesser extent on who someone is as a human being. The elderly people we have investigated have adjusted their goals and thus distanced themselves from the sometimes excessive need for active control in previous stages of their lives. There is more space for receptiveness, for 'passive' enjoyment, and for being guided rather than determining one's own life. Our respondents are considerably more vital and resilient when it comes to their processes of meaning-making than the participants from Van Wijngaarden's research – notably, the latter group have fewer illnesses and disabilities determining their lives than our respondents, who depend on permanent care.

In Chapter 6, we examine the views on aging in general of Hans-Martin Rieger (2008. *Altern anerkennen und gestalten. Ein Beitrag zu einer gerontologischen Ethik [Acknowledging and giving shape to growing old].* Leipzig: Evangelische Verlagsanstalt) in relation to the experiences and opinions of the elderly people we investigated and who depend on permanent care. The core of Rieger's vision is that one must acknowledge ('anerkennen') and accept ('annehmen') one's growing older and then shape it according to one's ability ('gestalten'). Expressed in one continuous movement: say yes to life, in other words: positively accept life,

even when one grows older and may have to encounter more difficulties in one's life.

The elderly people investigated by us indeed appear to live the way Rieger has in mind, even though they depend on permanent care, which means seriously aggravating circumstances.

To be sure, not everyone manages this situation equally well. Whether or not one is able to adjust oneself to the circumstances is a question which can be answered at different levels, varying from resistance to surrender, from dull resignation to full and positive acceptance. Awareness of one's condition and communicative and social skills are crucial additional factors, which are not mentioned by Rieger. The same applies to factors like humour, the supportive strength of a community and a sense of gratitude, factors to which Rieger pays hardly any attention, but all of which appear to play an important role. In the end, personal convictions are decisive: inner acceptance opens new paths that are leveled with adaptability and walked upon with willpower and courage, while motivation helps to keep one going. Post-traumatic growth becomes particularly visible in transcendence or greater awareness: people open up to things they did not pay attention to previously, they are closer to their emotional life, more connected with nature and living more in the here and now. Apart from that, personal growth demonstrates itself in generativity (previous and younger generations become more important than oneself) and a diminishing attachment to material things (gerotranscendence). It also leads to feelings of gratitude and satisfaction with life.

All in all, it is quite remarkable that the elderly people we investigated are succeeding quite well usually in shaping their lives in a positive way, as we conclude in chapter 7. How they perceive their own health is in many cases at odds with their objective medical health, which could be interpreted as an indication of vitality and the positive effects of experiencing value, meaning and relevance in one's life. Ageing well requires – as our research shows clearly – an active attitude, not one of resistance, but of inner acceptance: practicing the art of ageing: not as the dreamed of 'eternal youth', but as a confident 'éminence grise'. The different ways in which the elderly people we investigated deal with the situation in their lives now, makes it possible to draw a considerably more subtle picture than the well-known black and white of 'failure' or 'success'.

On the basis of our research, we attempt to sketch how the complicated process of creating meaning might be functioning. Our own speculative model is very similar to that of Lawton (M. P. (1983). Environment and other determinants of well-being in older people. *The Gerontologist*, 23, 349–357), in which all relevant factors seem to be influencing each other. According to Lawton the various domains are equal in terms of potential influence. We see that meaning as a phenomenon each time has both an affirmative (the ability to experience meaning) and a stimulating effect (wanting to convey meaning) in relation to the other relevant elements. In its essence, the experience of meaning is based on the ability (which includes both wanting and being able) to existentially search for meaning, give meaning and importance to one's life and to experience meaning in it. Whoever is unable or less able to do this, is more likely to get stuck in life.

We then point to some limitations of our research project, such as that no quantitative research has taken place and there is no systematic literature review.

Among other things, we recommend further research into the influence of disease and

disability on the meaning-making system of elderly people, more (observational) research on elderly people with whom it is challenging to communicate due to sensory or cognitive disabilities or apathy. And we warmly plead for more interdisciplinary and multidisciplinary coordination and collaboration.

For the practice of intensive care, we make some recommendations, such as to focus on a more person-oriented individual approach than at present can usually be offered, to give more attention to people's passions or their enjoyment of life. Also, to offer perspectives for meaning: elderly people dependent on permanent care want to be enabled to do something for other people, too.

With regard to policy and politics, we advocate, among other things, more freedom of choice between living at home and in a care environment, to do more justice to one's self-control and autonomy and to the individual needs and desires, a re-evaluation of the concepts of autonomy and self-control and an eye for the value of a caring community ('Zorggemeenschap') that can help people find back their own life.

An extensive list of literature references concludes the whole, followed by a few appendices.