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Ready to give up on life: The lived experience of elderly people who feel life is completed and no longer worth living

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ABSTRACT

In the Netherlands, there has been much debate on the question whether elderly people over 70 who are tired of life and who consider their life to be completed, should have legal options to ask for assisted dying. So far there has been little research into the experiences of these elderly people. In order to develop deliberate policy and care that targets this group of elderly people, it is necessary to understand their lifeworld. The aim of this paper is to describe the phenomenon 'life is completed and no longer worth living' from a lifeworld perspective, as it is lived and experienced by elderly people. Between April to December 2013, we conducted 25 in-depth interviews. A reflective lifeworld research design, drawing on the phenomenological tradition, was used during the data gathering and data analysis. The essential meaning of the phenomenon is understood as *'a tangle of inability and unwillingness to connect to one's actual life'*, characterized by a permanently lived tension: daily experiences seem incompatible with people's expectations of life and their idea of whom they are. While feeling more and more disconnected to life, a yearning desire to end life is strengthened. The experience is further explicated in its five constituents: 1) a sense of aching loneliness; 2) the pain of not mattering; 3) the inability to express oneself; 4) multidimensional tiredness; and 5) a sense of aversion towards feared dependence. This article provides evocative and empathic lifeworld descriptions contributing to a deeper understanding of these elderly people and raises questions about a close association between death wishes and depression in this sample.

1. Introduction

In recent years, there has been a growing scientific interest in elderly people wishing to die without the presence of a life-threatening disease or a severe psychiatric disorder. Several quantitative studies have been undertaken to determine prevalence rates, characteristics and risk factors associated with the development of death ideation and death wishes in elderly people who are tired of living (Harwood et al., 2001; Jorm et al., 1995; Rurup et al, 2011a). In addition, some qualitative studies have been conducted to understand suicidal feelings in elderly people (Crocker et al., 2006; Harwood et al., 2006; Kjølseth et al., 2009; Kjølseth et al., 2010; Rurup et al., 2011b; Rurup et al., 2011c). These studies indicate that age-related losses, decreasing sociality, depressive feelings, personal characteristics and beliefs are associated with the development of a wish to die.

Most elderly people who wish to die "will wait until time fulfils their wish" (Rurup et al., 2005) and would probably consider suicide to be unacceptable, associated with despair and mutilation. In the Netherlands, however, the general public seems to have become more open towards the possibility of a self-directed death (Van Delden et al., 2011). With the ageing of the baby boom generation an ethos of neo-liberal values such as self-determination, autonomy and individualism has become more dominant and has stimulated an on-going process of a growing awareness of death and dying, not only in the Netherlands but in the Western world as such (Chabot and Goedhart, 2009; Seale et al., 1997). The debate on how to determine time and manner of death has become more common, as these aspects are considered as important indicators of a 'good death' in western countries (Chabot and Goedhart, 2009).

Chabot and Goedhart (2009) studied individuals who have a strong desire to control and hasten death by committing auto-euthanasia. Auto-euthanasia refers to an intentional act of a

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person independently ending one's life; based on a persisting wish to die; decided after careful consideration, preferably after having discussed it with meaningful others; implemented in a careful manner, and without a physician performing euthanasia (Chabot and Goedhart, 2009). The term auto-euthanasia was previously used by Glaser and Strauss to indicate a way "to die gracefully, to manage one's own death and arrange a painless, easy departure, to forestall an indefinite prolonging of medical treatments, before one may be powerless and no longer capable of expressing one's will" (Glaser and Strauss, 1965). Although "the why and how of the hastened death" has been studied by Chabot and Goedhart (2009), prevalence figures on elderly committing auto-euthanasia are not available.

In addition, several recent studies indicate that an increasing number of Dutch people can imagine appreciating having a physician assist them in the dying process, even if they do not suffer from a serious disease (Buiting et al., 2012; Van Delden et al., 2011; Van Holsteyn and Trappenburg, 1998). Although in the Netherlands euthanasia and physician-assisted suicide are only permitted in cases of unbearable and hopeless suffering that stems from a medical condition, a growing minority of the general public supports physician-assisted suicide or euthanasia in cases of elderly people who do not suffer from a medical condition but who are tired of living (Raijmakers et al., 2013; Van Delden et al., 2011). Buiting et al. (2012) have demonstrated a significantly growing level of support for the availably of a last-will-pill from 31% in 2001 to 33% in 2005 up to 45% in 2008.

This growing support needs to be interpreted in the context of an on-going public debate in the Netherlands, questioning whether elderly people with a wish to die – without a life-threatening medical disease - should have legal options to ask for assisted dying. Since 2010, this debate is placed firmly on the Dutch parliamentary agenda by a citizens' initiative called 'Out of Free Will', that collected 116.871 signatures to legalise assisted suicide for people over 70 who feel life is 'completed' and prefer death over life. Given these trends, a research agenda 'Elderly and a self-chosen death' (2014) was formulated at the request of the Dutch government, addressing several important questions in the end-of-life debate including the following: What are characteristics, prevalence rates and life-problems associated with this group of elderly people? How do shifting socio-cultural value orientations impact their wish to die? What is the role of a physician in these cases? What practical interventions may be suitable to diminish the wish to die and improve quality of life? What ethical and legal questions are raised and must be answered?

To answer these questions and to develop policy and effective health care services for elderly people who feel their life is 'completed' and wish to die, it is a prerequisite to first hear their voices and address their inner perceptions and subjective experiences. However, as described in a literature review undertaken by the authors of this article (Van Wijngaarden et al., 2014), very little qualitative research has been conducted into the experiences of this specific group of elderly people who wish to die without having a serious medical condition. It is thus necessary to supplement existing knowledge with in-depth knowledge about the lived experiences of these elderly people. The aim of this study was to develop an in-depth understanding of the phenomenon that 'life is completed and no longer worth living' as it is lived and experienced by elderly people who do not suffer from a life-threatening disease or a psychiatric disorder. This was done from a phenomenological approach to explore this experience with an open, non-judging and wondering attitude (Van Manen, 2014).

2. Methods

2.1. Reflective lifeworld approach

In order to describe the phenomenon in all its richness, an in-depth interview study based on Dahlberg's reflective lifeworld approach (Dahlberg et al., 2008) was conducted. This approach, inspired by the philosophical phenomenology, was chosen because of its primary focus on the lifeworld: the world of lived experience. Rather than giving causal, behavioural explanations and using external theories and interpretive frameworks, the focus is on giving a description of the phenomenon as it is experienced by those who are studied (Finlay, 2011). The aim of the reflective lifeworld approach is "to illuminate the essence of the phenomenon" under research. For Dahlberg (2006), an essence refers to a common thread through the variety of participants' experiences; the essential characteristics of the phenomenon "without which it would not be that phenomenon".

To enable the phenomenon to reveal itself, researchers need an open attitude. This phenomenological attitude requires the practice of "bracketing", which includes all efforts made to restrain researcher's personal ideas and scientific assumptions from having an uncontrolled effect on evolving understandings, in order to examine the phenomenon in a systematic, open and careful way (Finlay, 2011). It demands "a true willingness to listen and see and understand" (Dahlberg et al., 2008). To practice this phenomenological attitude during this current research project, there was ongoing reflection (by means of a reflective research journal and dialogue with co-authors and peers). This enabled the researcher to reflect on evolving understandings and to bracket 1) scientific theories and explanations, 2) truth or falsity claims made by participants, 3) and personal views and experiences of the researcher (Finlay, 2011).

2.2. Participants and sampling

Twenty-five people over 70 years of age, who considered their life to be 'completed' and no longer worth living, and who strongly wished to die while not being terminally or mentally ill, participated in an in-depth interview exploring their lived experience. Persons were recruited between April and September 2013. Advertisements were placed in four Dutch magazines and on three Dutch websites, all targeting elderly people. In these advertisements, the context and aim of our research project were described. One hundred forty-four people responded by post, email or telephone, giving a description of their personal situation. Every respondent received a response with a short personal acknowledgement followed by general information about the selection procedure.

Participants were purposefully sampled in two rounds: the first selection was based on respondents' short personal description. Sample criteria were: richness of experiences; differences in (physical) health; different ideological and demographic backgrounds; and nationwide coverage. Next, potential participants were called by the interviewer to ensure the first selection. Some potential participants were then excluded, as they turned out to be so-called "*if-then* respondents": *if* their situation declined further, *then* they would prefer to have legal options for assisted dying, rather than having an actual wish to die at that moment. Others were highly politically driven. Their response was focused on advocating legalization of self-directed death, instead of giving a personal, experiential account. In a few cases, the respondents withdrew. One participant, who was aged 67 at the time of the interview, was included because of her unique religious background. Table 1 shows all background characteristics of the selected