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“Life goes on”: Perspectives on the will to live from residents of Swiss long-term care facilities

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Abstract

Objectives. While there is a growing body of literature on the wish to die in older patients, there is little research about their will to live. Exploring the subjective will to live (WTL) offers valuable insights into the patients’ resources and motivations, which could help improving geriatric palliative care. The aim of this study was to examine, in long-term care facilities (LTCF), residents’ definitions of and factors influencing their WTL.

Methods. Twenty residents (mean age 85.8 ± 10.3 years, 70% women) of 3 Swiss LTCFs gave informed consent and participated in semi-structured interviews about their WTL. Interviews were audio-recorded and transcribed verbatim. Thematic analysis was conducted to identify recurrent themes (40% double coded).

Results. The majority of residents reported that they had not thought about the WTL. Nevertheless, they had no difficulty in describing it as innate in their lives. They spontaneously mentioned factors that contributed to their WTL, classified into 5 themes: (1) relationships – primarily with family and health professionals, secondarily with other residents; (2) living situation – the LTCF as a necessary place providing care, constant professional presence, and security, yet necessitates inconveniences such as loss of independence; (3) personality factors – positive outlook on life or spirituality; (4) engagement in routines – organized activities and individual daily routines; and (5) health status – primarily related to functional health.

Significance of results. Examining WTL provides important insights into elements that are essential to take into account in planning care and promoting well-being in LTCF residents. The themes identified provide important starting points for improving life in LTCFs.

Introduction

Offering health care that improves older patients’ well-being is challenging. Residents of long-term care facility (LTCF), in particular, often have complex geriatric palliative care needs and increased vulnerability (Ersek et al. 2022). The will to live (WTL), defined as “the psychological expression of one’s commitment to life and the desire to continue living, encompassing both instinctual and cognitive-emotional components,” (Shrira et al. 2019, 1) is a valuable indicator of subjective well-being in older people (Bornet et al. 2021a). Exploring LTCF residents’ WTL may facilitate a deeper understanding of their lives and impact clinical practice through person- and resource-oriented care planning (Bornet et al. 2021b). A recent study indicated that LTCF residents expressed a strong WTL and that higher WTL was associated with better physical mobility (Bornet et al. 2021b). Research into the WTL is usually based on single-item numerical rating scales that measure intensity, with a consensus that the WTL is self-explanatory and well-understood (Bornet et al. 2021a). These studies have been conducted with patients in psychiatric, geriatric, palliative, and oncology care settings (Bornet et al. 2021a).

Fewer studies have explored the WTL with a qualitative approach. These have focused on patients who attempted suicide, aiming to better understand their life-and-death struggle; they have shown that being connected to others is crucial to the WTL (Sifneos and Mc Court 1962; Vatne and Naden 2016). Research on community-dwelling older people in Israel has highlighted the importance of social networks, along with religious faith and nationalism-related emotions, in the WTL (Carmel et al. 2016; Zamir et al. 2020). However, to the best of our knowledge, there is no qualitative data yet on the WTL among LTCF residents. The aim of the present study was

to explore how older LTCF residents define the WTL and which factors they see as contributing to the WTL.

Methods

Design and participants

This cross-sectional qualitative exploratory study is part of a multi-method study in Swiss LTCFs (Bornet et al. 2021b). Participants were selected for inclusion by the physician of the LTCFs when they were over 65 years of age, were able to speak conversational French, retained decision-making capacity, and were able to give written informed consent. Of the 236 residents screened, 114 were not eligible, 19 did not consent, and 103 consented to participate (Bornet et al. 2021b). From this total of 103 participants included in the multi-method study, we conducted a semi-structured interview with 20 participants (in addition to the other questions of the multi-method study). This interview was conducted with the consecutive 6 to 7 first participants among 3 LTCFs. All 20 were asked to record this interview and agreed. The interview explored their definition of the WTL and factors contributing.

Procedure

In-person, semi-structured interviews were conducted at the 3 LTCFs by a physician with 6 years of experience in geriatric research and clinical practice. Residents were not treated by or known to the interviewer. The interviews took place in a private room where the interviewer was alone with the participant. Interviews began with an open-ended question: "As a researcher, I am interested in the 'WTL.' Have you ever thought about it?" This was followed by probing questions exploring residents' definition of the WTL and factors influencing their WTL. Probing questions had been prepared beforehand and tested with the other members of the research team. Median interview length was 23 min (range: 13–79 min). Interviews were audio-recorded and transcribed verbatim.

Analysis

Themes were identified inductively at a semantic level through thematic analysis (Braun and Clarke 2022). First, the interviewer (first author) along with the second author, a psychologist, listened to all interviews and took detailed notes and discussed these. Then, 40% of the interviews were double coded; 2 were coded initially and a draft framework was developed, then 2 more were coded and the framework adjusted, and finally 4 were coded in parallel and the discrepancies in coding were discussed and the framework readjusted (total double coded = 8). The interviewer then coded all the remaining data; the second author verified this coding. NVivo software (QSR International, Melbourne, Australia) was used to manage and categorize the data. Analysis was conducted in French, and extracts presented in the results section have been translated from French into English by a native English speaker.

Results

Demographics

The mean age of the participants was 85.8 years (range: 66–100 years; SD = 10.3), and 70% were women. They received a mean of 138 min (range: 52–282 min; SD = 59) of daily care

(Tilquin and Roussel 1993), and the mean duration of their residence at the LTCF was 2.6 years (range: 0.2–6.0 years; SD = 1.8).

Definitions and emerging answers

When asked about their WTL, LTCF residents commonly responded that they had not thought about their WTL before; however, many residents immediately followed such a response with a reflection on the "innate" nature of the concept of the WTL.

"I don't even think about it; in the end, [life] follows its path. It's not a question of whether we want to live or not – that's how it is." [Participant no. 12, female, 95 years old]

Some residents initially indicated that they did not know how to respond when questioned about their WTL and that it was difficult to put into words:

"I can't say that I like my life; it's restrained. But, even still, I like everything that is life, everything that is ... I can't explain." [Participant no. 18, female, 87 years old]

After the initial question, and most often before asking them the question, residents spontaneously discussed factors that contributed to this WTL. We have classified these factors into 5 main themes: relationships, living situation, personality factors, engagement in routines, and health status.

Relationships

Contact with family and loved ones was the primary factor discussed in relation to the WTL. Families were described as giving meaning to life and providing help and support. In addition, residents reported that family gave them an important sense of the need to "keep going," that being present for their loved ones was important to them:

"The family members [are important] so that we know that we are not alone on earth, after all." [Participant no. 12, female, 95 years old]

Some residents, particularly those who did not have family present, discussed their relationships with friends, some of whom had died:

"I've got some neighbors who are charming; they come and see me all the time." [Participant no. 4, female, 95 years old]

In relation to their contact with other residents, some participants discussed the difficulty of establishing meaningful connections due to health and cognitive difficulties:

"Developing contacts in an [LTCF], in my opinion, is not easy. There is nothing to talk about. We're not interested in anything. At the dinner table, I'm now with 2 ladies, but there is nothing to talk about. If I don't try to make small talk, we spend 1 hour together without saying a word." [Participant no. 16, male, 96 years old]

Other residents also discussed the need to be discrete with other residents and to make sure that one does not intrude, as they share a living space:

"I'm not very talkative and I don't want to know other people's worries." [Participant no. 7, female, 79 years old]

Also, relationships with LTCF staff were described as being important for the residents' WTL. Relationships with nurses, with

whom they were in daily contact, with other caregivers and kitchen staff, while not as strong as their relationships with loved ones and friends, were described as a constant presence that was positive most of the time and negative sometimes and had an impact on their WTL:

“You are a whole person, not a number here.” [Participant no. 15, male, 69 years old]

“The staff around us: if they are in a good mood, everything is fine. If they’re not in a good mood, it’s not okay.” [Participant no. 1, female, 70 years old]

Residents also noted the difficulties associated with working in a LTCF, demonstrating deep understanding and empathy for their caregivers:

“They do everything closest to their soul; their work is not easy.” [Participant no. 15, male, 69 years old]

Living situation

Residents recognized that they could no longer live at their homes given the care they needed. The LTCF was seen as a place that provided necessary care, which provided them with comfort and security:

“I like being alone, but when I have difficulty getting dressed, I’m happy to have someone.” [Participant no. 14, female, 82 years old]

Through the constant presence of health-care professionals and staff, LTCFs offered safety and serenity, both for the residents and for their loved ones:

“If I’m at my house, I can fall. Once I laid on the floor for 2 hours. Here, that won’t happen to me.” [Participant no. 13, female, 100 years old]

Residents were confident in the care they received, which they described as high quality and personalized, thanks to dedicated caregivers who adapted to each resident:

“I think you can’t find better care than what we receive here. [The professionals] are so caring. They say to me: ‘tell us if you need anything, we are here for you.’” [Participant no. 11, female, 94 years old]

Sometimes, residents felt that the staff cannot provide enough support. They explained these situations by a lack of resources:

“[The nurses] are in a hurry in the evening. They come to my neighbor, give her the medicine, then they leave right away. I say to myself ‘my God,’ but my poor neighbor, she has trouble swallowing her medicine and she still has to drink her glass of water. [The nurses] leave before she’s finished. I think it’s a shame.” [Participant no. 6, female, 85 years old]

Life in the LTCF is discussed as being associated with a loss of independence, particularly regarding decision-making. The residents noted that they missed the autonomy and privacy that they had in their homes, but that there were positive aspects to being in an LTCF, such as living in a lively place and having organized activities:

“I am rather solitary, but I am not against friendship and living together because, to live here, you still have to accept everyone, whoever they are. Whether you appreciate them or not, we’re all here.” [Participant no. 3, male, 84 years old]

Residents also discussed their natural and architectural surroundings as important to their WTL:

“We’re in a marvelous spot. Look, it’s beautiful, right? The interior too, it’s been well thought out.” [Participant no. 13, female, 100 years old]

Personality factors

Residents spontaneously mentioned that their WTL was intimately linked to their personalities; this personality had guided their way of life throughout their entire lives, and it remained constant at the LTCF.

First, residents mentioned the importance of having a positive outlook on life, which helped them face the difficulties they experienced in general but also at the LTCF. Appreciating beauty or showing gratitude contributed to this positive mindset:

“I am brought to life by nature; I’m quite positive. I always say: ‘it will be better tomorrow.’ And then it’s true, it actually happens to be true. I am very cheerful by nature. I was lucky enough.” [Participant no. 11, female, 94 years old]

The residents mentioned the importance of a “fighting spirit” and a will to “keep going” and “not give up” while living at the LTCF:

“I’ve always been active, that’s it; I can’t stay still. You must always move forwards.” [Participant no. 9, male, 66 years old]

The residents also discussed the importance of being able to adapt to their situation. They expressed the need to accept their unavoidable circumstances, even though the situation may not be as they would have hoped:

“I’ve always had a [WTL]. Whatever happens to me, I take it: I accept it. Whether it is bad or good, I have to accept it, because it’s too hard otherwise.” [Participant no. 18, female, 87 years old]

Sometimes residents expressed that living was a joy; they discussed their “zest for life” and considered living a pleasure. When they discussed this joy, they also mentioned “taking things day by day”:

“I like living for everything, everything makes me happy – that gives me pleasure. I take things day by day.” [Participant no. 2, female, 96 years old]

The residents’ WTL was also associated with connections to higher beings – a transcendent and intrinsically strong value. Some residents referred to their connections with God and discussed the intrinsic and innate value of life:

“Yes, there are things that we appreciate, like being with our loved ones. Yet, there is more than that; it’s deeper. It is something spiritual. It is the faith that we can have in an entity that is superior to us.” [Participant no. 3, male, 84 years old]

A connection with life outside of the LTCF was also reported to be important in maintaining their WTL. Keeping themselves informed and involved in life took many forms, such as reading the newspaper, following the news on TV, and a general desire to know about the happenings in the world:

“We have the newspaper at breakfast time [...] I like being aware of everything.” [Participant no. 8, male, 93 years old]

Engagement in routines

The residents spoke about the need to stay active and to participate in life at the LTCF, particularly through the activities organized by the LTCF:

“I still do some things, like going out with the [LTCF] bus, even if it takes effort. Being with people, talking, hearing what others are saying, it's part of life.” [Participant no. 13, female, 100 years old]

In addition, residents spoke of daily routines like mealtimes:

“At 3 o'clock, it's 'snack time,' they call it. There is something to eat. Then, I always ask for a fruit syrup. [laughs] That suits me very well.” [Participant no. 20, male, 96 years old]

Residents also spontaneously discussed the need to maintain their own routines when living at the LTCF, which helped to maintain their WTL:

“I read the Bible; it already takes lots of time, every day [...] You must also be interested in life and stay up to date. And it's absolutely necessary to have an activity. I'm lucky, I paint, that takes a part of my time.” [Participant no. 16, male, 96 years old]

These personal routines, whether taking a walk outside of their room, watching television, or doing a creative activity, allowed residents to keep in touch with the life outside of the LTCF:

“Each day I walk a bit, I go each day a little, on a flat ground, to the big oak tree.” [Participant no. 2, female, 96 years old]

Health status

Residents' health status was primarily discussed either in relation to their functional health and activities that they were still able to perform or in that their health status prevented them from continuing their activities, especially regarding their functional autonomy:

“I'm thankful for my health. I'm thankful for the privilege that I have to be able to move around without help. It's a huge gift.” [Participant no. 20, male, 96 years old]

Very few residents discussed their physical health, and when they did, it was not directly in relation to their WTL; rather, their physical health was something that they contended with daily:

“I'm not too happy with my health: my hands hurt me, and my paralyzed arm. It could be better, but it's OK – I am not complaining.” [Participant no. 15, male, 69 years old]

Similarly to physical health, emotional state and mental health were discussed by the residents in passing, not specifically related to their WTL, but important nonetheless, for example, in maintaining connections that are important to them:

“I also need to be able to keep my head in order to reason and to realize what is happening around me. If I were to lose my mind, obviously I would also lose the connections that link me to my son.” [Participant no. 3, male, 84 years old]

Some residents highlighted that their current WTL was conditional and depended on maintaining their current health status or, at least, not suffering:

“If my legs hurt or I'm completely lost, oh well, then I wouldn't have so much pleasure in living. I'm going to say, 'I have to go,' and that's all. Yes, if

I don't really know what I'm doing anymore, or if I ramble a little, then I'd be happy to go away, to leave.” [Participant no. 2, female, 96 years old]

While they expressed a WTL, the residents also understood the fact that the LTCF represented the final stage of their life and the fact they did not want overly invasive care. Although this fact was sometimes recounted with sadness, they were serene because they were convinced that the caregivers would take good care of them until the end of their lives:

“They take care of us.. I don't think we can find better [care]. You can say that I am very, very happy for the end of my life, to stay here.” [Participant no. 20, male, 96 years old]

Furthermore, residents were in an environment where they often saw other people whom they considered to be in a worse health state. Residents showed strong empathy for their peers and took into consideration that their peers may be affected more than themselves:

“I still have the taste for life. When I see everything around us. And here, it is worse: there are people who can't speak at all anymore, and people who have pain everywhere.” [Participant no. 14, female, 82 years old]

Discussion

Overall, residents describe the WTL as innate in their lives and linked to relationships, living situation, personality factors, engagement in routines, and health status. By examining the residents' own perspectives, these results paint an overall positive vision of their life in LTCFs. A key element is certainly that most the interviewed residents are able to live in the present, with realism and adaptability.

To our knowledge, this is the first study to explore residents' views about the WTL in a LTCF setting. Our findings about the importance of connection with others corroborates previous qualitative research conducted with patients in psychiatric care (Sifneos and Mc Court 1962; Vatne and Naden 2016). In LTCFs, as in other settings, the WTL can be explained by contributing factors extending beyond health-related aspects (Bornet et al. 2021a). These findings are coherent with a longitudinal study of 528 LTCF residents, which only showed a temporary drop in quality of life immediately after admission, reflecting associated psychological distress, and then no additional decline, highlighting residents' ability to adapt to the LTCF setting (Villeneuve et al. 2022).

Residents' emphasis on their adaptability to various situations should remind health professionals and society to critically reconsider preconceived ideas about the WTL of institutionalized older people. Indeed, it has been shown that both relatives and health professionals underestimate LTCF residents' WTL intensity in proxy assessments (Bornet et al. 2021b). This is explained in part by ageism, which tends to make LTCF a stigmatizing setting (Dobbs et al. 2008). These findings may have important implications for care planning and decisions around treatments aimed to maintain or prolong life, which are often based on residents' presumed WTL and quality of life.

The importance of relationships to residents' WTL includes the impact of the staff members' mood and energy levels, which are affected by their investment in their work. This highlights the need to examine and improve the working conditions of staff, not only for their own benefit but also for the well-being of the residents they care for. These results add to previous results showing that

staffing levels and staff attitude are linked to quality of care in LTCFs (Gilbert *et al.* 2021; White *et al.* 2020).

Implication for clinical practice and research

In our opinion, explicitly discussing WTL may contribute to a better understanding of the residents, both for staff and residents' loved ones. As an illustration, many advance care planning models include open-ended questions about the WTL (Bosisio *et al.* 2021). Consideration should also be given to including this topic for discussion at other times, such as when a resident first enters the LTCF or during follow-up, as a catalyst for discussions about the resident's current experience.

Given the importance of relationships for residents, the involvement of LTCFs' professionals must be further highlighted, both to strengthen professionals' posture and to contribute to an improvement in their demanding working conditions (Simmons *et al.* 2022). The most striking example is one of nursing assistants during the first wave of COVID-19. They felt abandoned and lacked adequate resources but developed strategies for coping with the situation (Bergqvist *et al.* 2023). Support of LTCF staff through person-centered care training is fundamental to improving working conditions and reducing turnover (Rajamohan *et al.* 2019). A recent consensus report from the American National Academies of Sciences also highlighted the need for additional financial resources (National Academies of Sciences, Engineering, and Medicine 2022).

Study limitations

While participants had no difficulties identifying negative aspects of their living situation, they were interviewed by a researcher and physician and thus may have reported a more socially desirable version of their experience. An additional selection bias may be present since all interviewed patients had agreed to participate in the larger study on the WTL. However, the latter study had a consent rate of 84.4%, which argues in favor of representativity. Finally, this study did not include participants without decision-making capacity, which precludes generalizing the results to all LTCF residents.

Conclusion

The findings of this qualitative study provide new insight into the meaning attached to the concept of the WTL for older institutionalized people. In addition to offering important information for decision-making, these results can constitute a basis for reflection on interventional measures aimed at promoting resource-oriented care in this context. The multidimensional nature of the WTL highlights the need to design care facilities with a shared commitment that involves residents and their loved ones, as well as health-care teams, governments, insurances, and researchers (National Academies of Sciences, Engineering, and Medicine 2022).

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