Original Article

Will to Live in Older Nursing Home Residents: A Cross-Sectional Study in Switzerland

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Abstract

Context. The will to live (WTL) is an important indicator of subjective well-being. It may enable a deeper understanding of the well-being of nursing home residents.

Objectives. To evaluate the intensity of WTL, its association with various factors, and its temporal evolution among residents ≥ 65 years old; we also aimed to compare it with proxy assessments of WTL.

Methods. A cross-sectional study was conducted in five nursing homes in Switzerland. Participants with decisional capacity were asked to rate the intensity of their WTL on a single-item numerical rating scale ranging from 0−10. A short-term follow-up was conducted among a sub-sample of 17 participants after three and six weeks. Proxy assessment by residents' next of kin and professional caregivers was conducted, and inter-rater agreement was calculated.

Results. Data from 103 participants (75.7% women, 87.3 ± 8.0 years) was analyzed. The median intensity of WTL was 8. Higher WTL was significantly associated with better physical mobility and shorter duration of daily care but not with age, gender, pre-admission care setting, or prognosis. Significant independent predictors of WTL were physical mobility and provenance from rehabilitative care. In the short-term follow-up assessment, WTL remained highly stable. Intraclass correlation coefficients were moderate for residents' next of kin and nurse assistants but poor for physicians and nurses; all proxy assessments underestimated the participants' WTL.

Conclusion. Nursing home residents expressed a very strong WTL and proxy aents underestimated residents' WTL. It seems pivotal to proactively communicate with residents about their WTL. J Pain Symptom Manage 2021;000:1−8.

Key Words

Will to live, wish to live, nursing homes, geriatric palliative care, older persons

Key Message

In this cross-sectional study, nursing home residents expressed a very strong will to live. Proxy assessments by next of kin or professional caregivers underestimated participants' will to live. The results calls for proactively and openly communicating with residents about their will to live.

Introduction

Offering healthcare that improves older patients' quality of life (QoL) is challenging, especially for nursing home residents, who often have complex health needs and increased vulnerability.[1,2] Nursing homes is their last place of life and they are accompanied until

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their death: in Switzerland, 35% of the population dies in a nursing home.[3] Providing appropriate care for nursing home residents requires attending to their wishes, needs, and well-being.

The will to live (WTL) is an excellent indicator of subjective well-being in older people.[4] WTL is described as "the psychological expression of one's commitment to life and the desire to continue living, encompassing both instinctual and cognitive-emotional components."[5] Tools for assessing WTL are usually based on numerical rating scales that measure intensity.[6] There are not yet any data available concerning the intensity of older nursing home residents' WTL.[6]

WTL is not just the opposite of a wish to die, which has been a much-studied topic to date.[7,8] For example, a study involving 280 residents living in nursing homes across Switzerland showed that only 4%−22% of residents expressed a wish to die, which was for almost all of them a passive wish for death to occur naturally.[9] Furthermore, WTL and a wish to die can coexist in the same person.[6] Therefore it is appropriate to explore WTL, as this may contribute to improving residents' QoL.[10,11] Addressing positive issues can foster communication between residents and professional caregivers and facilitate a resource-oriented outlook on care.[12,13]

Studies involving community-dwelling seniors and palliative care patients have shown that a stronger WTL is linked to improved QoL, better functional status, and more successful aging as well as decreased depression, and it has an inverse correlation with age.[6] No data are available on the proxy assessment of WTL and nursing homes are an ideal context in which to conduct a proxy assessment given that residents' next of kin often have to make surrogate decisions based on their assessment of residents' presumed wishes.[14]

In this study, we aimed to evaluate the intensity of WTL and the association of various factors with WTL and its short-term evolution among residents ≥ 65 years of age. We also aimed to compare resident assessment with proxy assessment of WTL.

Methods

Study Design and Setting

This cross-sectional study with short-term follow-up was conducted in five nursing homes[2] in the Canton of Vaud, a French-speaking region of Switzerland. These were not-for-profit institutions located both in the city and in the countryside, with a total of 289 residents (range: 48−83 residents per home). In these long-term care homes, the average age of admission is 84 years, the duration of daily care is 175 minutes, and the average length of stay until death is about two years.[15] Recruitment and interviews were conducted in January 2020 and from August to October 2020. The time interval between recruitment and interviews did not exceed 10 days. Due to the COVID-19 pandemic, the interviewer could not conduct recruitment and interviews during or immediately after residents' confinement periods, and the study was suspended from March to July 2020.

Instruments

WTL. The intensity of WTL was assessed with a single-item numerical rating scale, with 0 corresponding to no WTL at all and 10 corresponding to the strongest possible WTL.[6] According to a scoping review, this single-item assessment is the method of choice for assessing WTL in clinical or research contexts.[6]

Participants' handicap and intensity of care received. Participants' handicap in physical mobility (ability to move) and in activities of daily living (ADL) were scored on a scale from 1−9, with higher scores indicating higher dependence in physical mobility and ADL. The intensity of care received was measured as the duration of daily care in minutes. These measurement scales were extracted from the *PLAnification Informatisée des Soins Infirmiers Requis* (PLAISIR), a standardized global assessment tool for older people in nursing homes.[16] We used data previously collected outside of this research setting; trained nurses routinely collect these data, which are used in clinical practice and for billing purposes.

Prognosis. The prognosis was assessed by asking the nurse in charge a version of the surprise question: "Would you be surprised if this patient died within three months?"[17] Their answers were scored as 0 for no or 1 for yes, with the latter indicating good prognosis. This question, used in various study contexts including nursing homes, is a screening tool for identifying patients approaching the end of their lives. It helps identify those with a poor prognosis who may particularly benefit from palliative care.[18]

Demographic characteristics. Information about age, gender, duration of residence, and the resident's care setting prior to nursing home admission were obtained from administrative records.

Sample

The sample size was based on data reported by Carmel et al.,[4] and calculations were performed using the equation by Hulley et al.[19] Using a standard deviation (SD) of 1.5 and a 90% confidence level with a total interval width of 0.5, a sample size of 97 residents was deemed adequate. Estimating a 30% exclusion rate and a 50% refusal rate based on a previous study,[9] a recruitment pool of 280 residents was sought.

Recruitment Procedure

Eligible participants were nursing home residents aged ≥ 65 years of age. The exclusion criteria were the

inability to consent to participate in the study or to answer a question about one's WTL, as evaluated by the physician in charge, and an inability to speak conversational French.

Data collection was done successively in each nursing home. For each unit, the physician in charge assessed whether residents had the decision-making capacity required to participate in the study. Residents who met the inclusion criteria received letters informing them about the study and offering to meet with the interviewer in the next few days. At these meetings, the interviewer explained the study in detail and handed out written study information. Potential participants were given up to seven days to decide to participate. Residents who were willing to participate signed a consent form and were included in the study.

Study Participants

According to the physician in charge, of the 236 residents screened, 114 were not eligible and 122 (52%) were eligible for inclusion in the study. Among the residents eligible for inclusion, 14 did not consent, 4 had acute health problems, 1 died and 103 (84%) consented to participate. An analysis comparing participants (n = 103) with residents who did not consent (n = 19) did not show any significant differences (Supplementary Table 1). Participants' average age was 87.3 years (SD: 8.0), and 75.7% were women. Their characteristics are described in Table 1.

Table 1
Clinical Characteristics of the Participants

Characteristics		Participants (n = 103)
Age [yrs]	mean (SD)	87.3 (8.0)
	median (IQR)	88 (10)
	min−max	66.0−100.0
Women	n (%)	78 (75.7)
Handicap in physical mobility [NRS 1−9]	mean (SD)	7.5 (1.3)
	median (IQR)	7 (3)
	min−max	4.0−9.0
Handicap in activities of daily living [NRS 1−9]	mean (SD)	7.5 (0.6)
	median (IQR)	8 (1)
	min−max	6.0−8.0
Duration of daily care [minutes]	mean (SD)	170.6 (54.2)
	median (IQR)	170 (76)
	min−max	46.3−301.0
Duration of residence [days]	mean (SD)	864 (796)
	median (IQR)	636 (997)
	min−max	11−3712
Pre-admission care setting	n (%)	
Transitional short-term care		38 (36.9)
Home		23 (22.3)
Rehabilitation center		23 (22.3)
Acute care hospital		11 (10.7)
Other nursing home		8 (7.8)
Good prognosis	n (%)	72 (69.9)

Handicap in physical mobility and in activities of daily living: scores 1 to 9 (higher scores indicating higher dependency). Pre-admission care setting is where participants lived before admission to nursing home.
Abbreviations: IQR = interquartile range; NRS = numerical rating scale; SD = standard deviation.

Data Collection

WTL was assessed during a face-to-face interview, by a physician with six years of experience in geriatric research and clinical practice. The interviews took place in a private room where the interviewer was alone with the participant. The interviewer paid close attention to the study participants, listening attentively to each participant as they answered the questions.

At the end of the interview, the interviewer asked permission to contact the participant's next of kin. If this was granted, the interviewer contacted the next of kin by mail or phone and offered them the opportunity to participate in the study. If they chose to participate, they also received oral and written information and signed a consent form. Next of kin were asked to provide a proxy evaluation of the resident's WTL during a phone or in-person interview or by mail.

The interviewer also requested proxy evaluations of participants' WTL from the nursing home staff in charge (i.e., nurse assistants, nurses, and physicians). Nurses also answered a supplemental question about prognosis, the surprise question. Eleven physicians were involved, five of whom had board certifications in geriatrics. Medical and administrative data were collected from nursing home records.

For a convenience subgroup of participants selected from one nursing home unit, the interview was repeated after three and six weeks for a short-term longitudinal assessment of WTL. The proxy evaluations were not repeated.

Ethical Statement

The ethics commission of Canton Vaud approved the study (reference 2019−018925). The study was performed in accordance with Swiss legislation and the Declaration of Helsinki.

Statistical Analysis

Summary statistics of the variables are described as means, SDs, medians, interquartile ranges, minimums, maximums, or proportions. Between-group comparisons were performed using the two-tailed Student's t-test for continuous variables and the chi-squared test for categorical variables. Simple and multiple linear regressions were performed with WTL as the dependent variable. To describe the evolution of the longitudinal subgroup, changes in the mean were calculated. Inter-rater agreement was analyzed with the intraclass correlation coefficient. Statistical significance was established at $P \leq 0.05$. Participants had no missing data. Statistical analyses were performed using R version 4.0.3 (www.r-project.org).

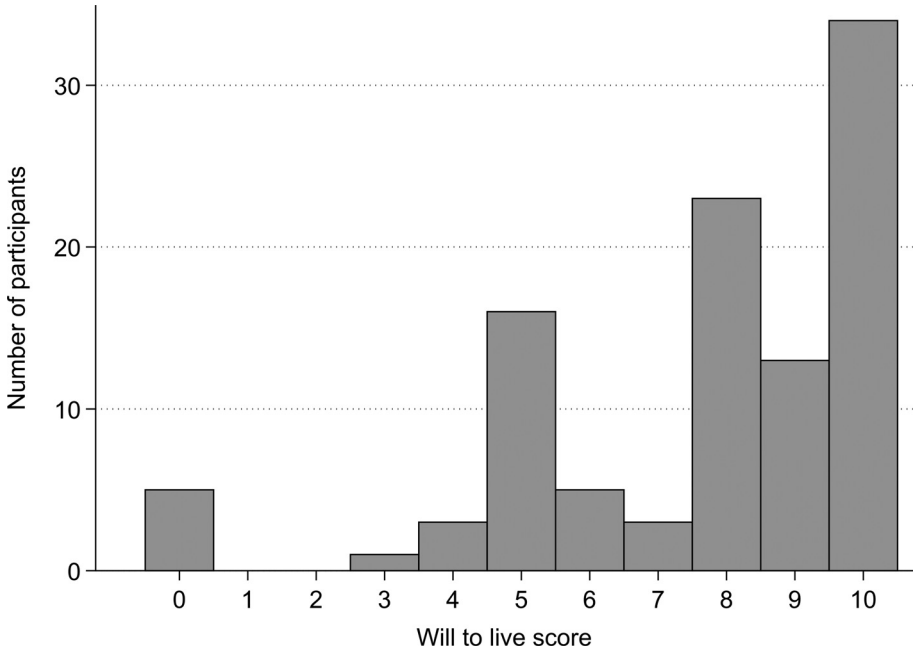

Fig. 1. Distribution of will to live scores, rating intensity of the will to live.

Results

Intensity of WTL

The mean WTL score was 7.6 (SD: 2.6), and the median score was 8 (interquartile range: 4). The distribution is shown in Fig. 1.

Factors Associated with WTL

Higher WTL scores were significantly associated with better physical mobility ($P = 0.006$) and a shorter duration of daily care ($P = 0.038$) (Table 2a). No significant association was found between WTL and age, gender, ADL, pre-admission care setting, or prognosis.

Multiple linear regressions revealed that higher physical mobility and pre-admission care in a rehabilitation center were significant independent predictors of WTL ($P = 0.054$ and $P = 0.039$, respectively) (Table 2b). The explained variation of all variables was $r^2 = 0.136$. Variance influence factors calculation did not show any collinearity.

Evolution of WTL

We followed up with a subgroup of 17 participants after three and six weeks. Their mean WTL scores were 7.88 (SD: 2.64), 7.53 (SD: 2.18), and 7.65 (SD: 1.93) for the first, second, and third assessments, respectively. In nine participants (53%), WTL scores remained stable between all three interviews, while three (18%) fluctuated, three (18%) increased, and two (12%) decreased. The mean difference in the WTL score was -0.35 (SD: 2.18) between the first and second assessment, 0.12 (SD: 1.50) between the second and third assessment, and -0.24 (SD: 2.19) between the first and third assessment. The differences were not significant, with *P*-values of 0.514, 0.750, and 0.664, respectively.

Proxy Assessment of WTL

Fifty-seven (55%) proxy assessments were conducted with participants' next of kin, 103 (100%) with nurse assistants, 93 (90%) with physicians, and 103 (100%) with nurses. Participants' next of kin included children (69%), extended family (17%), spouses (11%), friends (3%), and administrative representatives (1%), 61% of whom were women.

The proxy assessments and intraclass correlation coefficients are described in Table 3. The intraclass correlation coefficients were moderate for participants' next of kin and nurse assistants and poor for physicians and nurses.

Discussion

Intensity of WTL

This is the first study to evaluate intensity of WTL in a nursing home setting. A large proportion of residents expressed a very strong WTL. These findings are in line with previous studies in which WTL remained high even in psychiatric, geriatric, or palliative care patients.[6,20] Similarly, studies in nursing homes found that residents rated their QoL and life satisfaction favorably.[21,22] However, this result does not match with

Table 2

Analysis of (a) Simple, and (b) Multiple Linear Regression of Factors Associated with Will to Live Score, Rating Intensity of the Will to Live

Characteristics	(a) Simple Linear Regression			(b) Multiple Linear Regression		
	β (95% CI)	*P*-value	r^2	β (95% CI)	*P*-value	r^2
Age [yrs]	-0.01 (-0.08−0.05)	0.731	0.001	0.00 (-0.06−0.07)	0.911	0.136
Women	-0.30 (-1.49−0.90)	0.624	0.002	0.00 (-1.24−1.24)	0.994	
Handicap in physical mobility [NRS 1−9]	-0.54 (-0.93−-0.16)	**0.006**	0.072	-0.54 (-1.09−0.01)	**0.054**	
Handicap in activities of daily living [NRS 1−9]	-0.74 (-1.55−0.07)	0.073	0.031	0.09 (-1.12−1.31)	0.877	
Duration of daily care [minutes]	-0.01 (-0.02−0.00)	**0.038**	0.042	0.00 (-0.02−0.01)	0.636	
Pre-admission care setting			0.028			
Transitional short-term care	0.91 (-0.47−2.28)	0.194		1.22 (-0.16−2.60)	0.084	
Rehabilitation center	1.09 (-0.45−2.62)	0.163		1.67 (0.08−3.26)	**0.039**	
Acute care hospital	0.45 (-1.46−2.36)	0.638		0.27 (-1.64−2.18)	0.778	
Other nursing home	0.13 (-2.01−2.26)	0.908		0.36 (-1.77−2.49)	0.737	
Good prognosis	0.63 (-0.48−1.74)	0.261	0.013	0.72 (-0.45−1.89)	0.225	

Handicap in physical mobility and in activities of daily living: scores 1 to 9 (higher scores indicating higher dependency). Pre-admission care setting is where participants lived before admission to nursing home. *P*-values in bold represent statistical significance ($P \leq 0.05$).
Abbreviations: β = regression coefficient; CI = confidence interval; NRS = numerical rating scale; r^2 = coefficient of determination (for each characteristic for the simple linear regression and overall for the multiple linear regression).

the predominant public opinion about nursing homes.[23] Therefore, it may be relevant to increase public health literacy in this domain.

A portion had a low to moderate WTL, which may reflect the multi-step process of transitioning from having a WTL to a wish to die or even to hasten death.[8,24] Although some residents may have a WTL, they may also feel a passive wish to die and are waiting for their life to end.[9] Future studies need to concurrently assess WTL and the wish to die in order to elucidate the relation between these two concepts and their temporal dynamics. Overall, the results suggest four clusters of responses: absence of WTL (score: 0, 5% of participants), low to moderate WTL (score: 1−7, 27%), strong WTL (score: 8−9, 35%), and very strong WTL (score: 10, 33%). Assessment with a larger scale could confirm this hypothesis of four clusters.

Factors Associated with WTL

Our results show the importance of physical mobility as a determinant of nursing home residents' WTL. Previous studies in other settings described a link between functional autonomy and WTL.[5,25,26] These results are in accordance with a literature review indicating that functional autonomy is a major factor for residents' QoL.[27] An association between the duration of daily care and WTL was found in the simple linear regression, but not in the multiple linear regression, indicating the close relationship of WLT with physical mobility. The second independent determinant of WTL was pre-admission care in a rehabilitation centre, which may suggest that certain residents had benefitted from geriatric rehabilitation before admission. However, contrary to previous studies, we did not observe a link with the ADL, a broader concept that includes multiple heterogeneous personal skills.[6]

The absence of an association with age may be explained by the fact that in our geriatric sample, chronological age did not reflect a homogeneity of aging trajectories.[28] Neither was prognosis linked to WTL, indicating an independence of WTL from clinical status and reflecting that even residents close to death can have a very strong WTL.

Evolution of WTL

During the short-term follow-up, differences in the means were small and statistically nonsignificant. These results are in line with previous studies that showed strong test−retest reliability in WTL assessments.[4,29,30] Our data may indicate that WTL remains stable even beyond six weeks, but this must be tested in another study with long-term follow-up.

Table 3

Proxy Assessments of the Will to Live Score, Rating Intensity of the Will to Live

Characteristics		Next of Kin (n = 57)	Nurse Assistants (n = 103)	Physicians (n = 93)	Nurses (n = 103)
Intraclass correlation coefficient	Coefficient (95% CI)	0.59 (0.41−0.73)	0.57 (0.43−0.69)	0.49 (0.34−0.64)	0.39 (0.21−0.55)
Difference from participants' responses	Absolute mean (SD)	1.94 (1.63)	1.62 (1.72)	2.14 (1.72)	2.17 (1.72)
	Arithmetic mean (SD)	-1.17 (2.26)	-0.24 (2.36)	-1.26 (2.45)	-0.68 (2.69)

Abbreviations: CI = confidence interval; SD = standard deviation.

Proxy Assessment of WTL

Overall, the next of kin gave the best proxy assessment of WTL, followed by nurse assistants, physicians, and lastly, nurses. Random error was significant, with an average ranging from 1.62 for nurse assistants to 2.18 for nurses. Regarding systematic error, a general tendency to underestimate residents' WTL was shown, but this was lower for nurse assistants and nurses than for next of kin and physicians.

A previous study based only on nurses' proxy assessments revealed the interobserver agreement between two nurses to be lower for WTL than for other indicators, such as pain level or comfort status.[30] Our results suggest that it may be less the assessor's professional background but rather the total time spent with the residents that matters most in understanding their WTL. Other factors such as personality, proximity, and training in medical humanities, may be important to consider, perhaps even before biomedical training background is considered. Nurse assistants have the longest and most frequent interactions with residents, they build closer relations with them, and their relations are more strongly characterized by reciprocal personal aspects than by asymmetric medical and care aspects.[31] The next of kin who participated in our study had a close bond with strong commitment to, and good understanding of their loved ones, which explains their accuracy in the proxy assessments.[32] A study on proxy assessments of decision-making preferences also showed that next of kin better predicted patients' preferences than nurses and physicians.[33] As for nurses and physicians, their knowledge of diagnoses and biological elements could result in a poorer proxy assessment.

Nevertheless, proxy assessment is not as good as direct assessment by residents, as WTL is an inherently subjective dimension. This inter-rater gap has also been shown for QoL and well-being.[34,35] We observed a global underestimation of WTL, similar to previous studies that explored QoL.[34,36] It has been shown that difficult health problems have less impact on patients than others predict thanks to patients' adaptability.[36] The underestimation of older persons' WTL could be influenced by implicit ageist stereotypes, which have also been shown to complicate mental health assessments of older patients.[37] Thus, underestimating residents' WTL could be a form of ageism that has substantial consequences with respect to treatment decisions made by surrogates for incapacitated older persons.[38] It may be important to further explore this hypothesis, especially since previous studies have shown that negative stereotypes of aging weaken older people's WTL.[39]

Implication for Clinical Practice and Research

As it allows access to a subjective and global dimension of the residents, an assessment of WTL may help foster therapeutic alliances and person-centered care planning. The goals of care and the intensity of treatment should be personalized for each of the clusters identified (from an absence to a very strong WTL). Exploring WTL may also be an important conversation starter for conducting advance care planning with nursing home residents.[40] In this way, integrating the concept of WTL offers promising opportunities for nursing homes in terms of person-centered services driven by the needs of residents, which can empower residents to participate and share in decision making.[41,42]

Our results could have societal impact by correcting an overly negative view of older persons' lives in nursing homes. The participants of our study demonstrated that not only can nursing home residents have lives worth living, but their WTL can be high despite the circumstances of old age, dependency, and institutional context.

Study Limitations

This study has several limitations. First, no prior psychometric validation has been conducted in a nursing home setting for the single-item numerical rating scale that assesses WTL. However, validation has previously been conducted with older persons in other settings with good psychometric results.[6] Nevertheless, a lack of wording related to the scale's numbers could have reduced the participants' understanding of the numbers and their meaning. An assessment tool that incorporates this wording and is based on several items may offer better psychometric properties.[4] This issue may have influenced the division of the responses about the WTL into four clusters. Future studies should assess whether these groups are also present in the results when using other assessment methods. The longitudinal analysis employed in this study must be interpreted with care due to the small sample size and the possibility that residents' ability to rate could change as time progresses. Second, we could not rule out a social desirability bias during the WTL assessment. Nevertheless, the interviewer was external to the nursing home, and participants had previously been informed about the confidential nature of the interview. They also showed consistent answers during the short-term follow-up. Furthermore, previous studies have shown that social desirability does not seem to bias subjective well-being assessments among older persons.[43,44] Third, since proxy assessments occurred after participants' interviews, we cannot rule out that participants discussed their WTL with their next of kin or professional caregivers after the interviews. To limit this bias, proxy assessment was conducted promptly after the participants' one. Finally, although multicenter recruitment may strengthen external validity, additional studies are needed to generalize the results in other countries. At

the international level, Switzerland has a high rate of nursing homes beds per persons ≥ 65 years as well as high overall staffing levels, especially compared to the proportion of certified nurses.[45,46]

Conclusion

The WTL was high among Swiss nursing home residents and tended to remain stable, even for residents who were close to death. Physical mobility was a key determinant of the WTL. Proxy assessments were insufficient to fully understand residents' WTL, which underscores the importance of openly communicating with residents about their WTL. Our results encourage further studies on WTL, particularly how it could be promoted as a facet of holistic geriatric care, by improving residents' understanding.

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Supplementary Materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.jpainsymman.2021.05.006.

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