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A public health perspective on older adults’ end-of-life health literacy in Switzerland

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A public health perspective on older adults' end-of-life health literacy in Switzerland

Lausanne, le 13 décembre 2023

pour les Doyen·nes

Prof. Armin Von Gunten

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Summary

Healthcare has shifted from a paternalistic towards a patient-centered care model, highlighting the importance of individual decision-making, especially in the face of end-of-life challenges, which have been accentuated by the current aging population and medical technological advancements. This change emphasizes the need to explore individuals' health literacy skills that empower them to make complex end-of-life healthcare decisions. Despite its importance, research on end-of-life health literacy is limited. Recent studies, especially in Switzerland, suggest that many older adults lack an understanding of critical end-of-life healthcare options they or their loved ones might have to choose at some point in their lives. This PhD thesis presents a comprehensive synthesis of recent research findings exploring end-of-life health literacy among older adults in Switzerland using data from the Survey of Health, Ageing, and Retirement in Europe (SHARE). It also aims to introduce and validate a unique instrument tailored to measure individuals' subjective end-of-life literacy (S-EOL-HLS), i.e., their abilities to navigate end-of-life medical situations and enhance communication and decision-making in these contexts. The results from the different studies included in this PhD thesis show that in Switzerland, approximately one older adult out of three has low health literacy levels and experiences difficulties in managing health-related matters. Subgroups in the population at risk of having lower health literacy levels varied depending on important factors such as sex, education, financial difficulties, and self-rated health. In addition, significant misunderstandings persist about various end-of-life medical situations, with many overestimating the effectiveness of some treatments and underestimating others. Factors such as sex, financial difficulties, age, and differences between the linguistic regions were associated with these inaccurate perceptions. For instance, only 9.3% accurately understood the survival rates of cardiopulmonary resuscitation performed on a 70-year-old outside a hospital, with those who understood the cardiopulmonary resuscitation survival rates being significantly more inclined to prefer not to be resuscitated. Moreover, the introduced S-EOL-HLS tool appears to measure end-of-life health literacy among older adults effectively. Higher end-of-life health literacy scores are associated with better end-of-life knowledge and more proactive engagement in advance care planning. In conclusion, the highlighted studies collectively emphasize Switzerland's need to derive new and/or enhance existing public health policies that bolster older adults’ end-of-life health literacy skills to enable them to make better-informed choices, potentially leading to improved end-of-life healthcare quality for individuals, their loved ones, and healthcare providers.

Résumé

L'approche des soins de santé a évolué d’un modèle paternalistique vers un autre centré sur le patient, mettant en avant l'importance de la prise de décision individuelle, notamment face aux défis de fin de vie qui sont accentués par le vieillissement de la population et les avancées technologiques médicales. Ce changement souligne l’importance d'explorer les compétences en santé des individus leur permettant de prendre des décisions complexes. Malgré son importance, la recherche sur les compétences en matière de soins de fin de vie est limitée. Des études récentes, en particulier en Suisse, suggèrent que de nombreux adultes âgés n'ont pas une compréhension claire des options de soins de santé en fin de vie qu’eux-mêmes ou leurs proches pourraient devoir choisir. Cette thèse de doctorat présente une synthèse complète des recherches récentes sur les compétences en matière de soins de fin de vie chez les adultes âgés en Suisse, utilisant les données de l'Enquête sur la Santé, le Vieillissement et la Retraite en Europe (SHARE). Elle vise également à introduire et valider un nouvel instrument conçu pour mesurer les compétences subjectives des individus en matière de soins de fin de vie (S-EOL-HLS). Les résultats présentés dans cette thèse de doctorat montrent qu'en Suisse, environ un adulte âgé sur trois présente un faible niveau de compétence en santé et rencontre des difficultés à gérer les questions liées à la santé. Les sous-groupes de la population risquant d'avoir des niveaux plus faibles varient en fonction de facteurs importants tels que le sexe, l'éducation, les difficultés financières et l'état de santé auto-évalué. Par ailleurs, d'importantes incompréhensions subsistent concernant diverses situations médicales de fin de vie, beaucoup surestimant ou sous-estimant l'efficacité de certains traitements. Des facteurs comme le sexe, les difficultés financières, l'âge et les différences linguistiques étaient également associés à l'inexactitude de ces perceptions. Par exemple, seulement 9,3% connaissaient les chances de survie après une réanimation cardiopulmonaire pratiquée sur une personne de 70 ans hors d'un hôpital, les personnes connaissant les chances de survie étant nettement plus enclins à préférer ne pas être réanimés. La nouvelle échelle, S-EOL-HLS, semble mesurer efficacement les compétences en matière de soins de fin de vie chez les adultes âgés, avec des scores plus élevés associés à une meilleure connaissance des situations médicales de fin de vie et à un engagement plus proactif dans la planification anticipée des soins. En conclusion, les études mises en évidence soulignent la nécessité pour la Suisse de créer de nouvelles politiques de santé publique visant à renforcer les compétences en matière de soins de fin de vie des personnes âgées afin de leur permettre de faire des choix plus éclairés, ce qui pourrait conduire à une amélioration de la qualité des soins de santé en fin de vie pour les individus, leurs proches et les prestataires de soins.

Table of content

1. Introduction

1.1 Contextual overview

1.1.1 The relationship between patients and healthcare providers

Before delving deeper into the topic addressed in this PhD thesis, it appears important to clarify that even though this manuscript concentrates on particular facets of end-of-life medicine and health, it underscores the essential role of the humanities in healthcare as a pathway to establishing respectful and compassionate relationships between healthcare providers, patients, and their loved ones. Consequently, throughout this manuscript, the interpretation of the relationship between healthcare providers and patients closely aligns with that of Hellín (2002), which postulates that the roles of healthcare providers extend well beyond their scientific knowledge and technical expertise, requiring them to grasp the complexities of the human condition. Patients are more than just a list of symptoms, impaired organs, or disturbed emotional states. They are individuals, encapsulated in a mix of anxiety and hope, who pursue comfort, assistance, and reassurance. Therefore, the quality of the relationship between patients and their healthcare providers is crucial, as it often influences the accuracy of diagnoses and the effectiveness of treatments [1].

The relationship between patients and healthcare providers has undergone significant transformations over time. Tracing back to the Middle Ages, the relationship was similar to that between priests and their followers, where the understanding of illness had more spiritual aspects than medical ones [2]. Individuals saw diseases as divine punishment for sins. They thus tried to handle their fears of being weak, getting sick, and dying through various means, including religious and supernatural beliefs [2]. Doctors were viewed not just as medical experts but also as magical entities, held high societal ranks, and their patients were treated as helpless individuals [3]. Until the French Revolution, this one-sided dynamic in medical relationships persisted due to the absence of social and technological progress, but the Revolution period combined with the Age of Enlightenment highlighted the importance of liberalism, equality, dignity, and empirical science began to shift medical attitudes and behaviors significantly [4]. The model where the doctor was the primary decision-maker and the patient merely a passive follower moved towards a more collaborative approach; however, with illness still primarily defined by symptoms, the few doctors, mainly serving the upper-class and aristocrats, focused on interpreting individual symptoms rather than conducting thorough examinations [3].

The advent of hospitals in the late 18th Century, together with advancements in microbiological knowledge and surgical skills, catalyzed a transition from a symptom-focused treatment approach to diagnosing pathological lesions within the body, thus establishing the biomedical model of illness and further solidifying a paternalistic model in the doctor-patient relationship due to the amplified patient dependency on doctors' clinical and anatomical expertise [5]. By the late 19th century, the paternalistic model began evolving due to the emergence of psychology and psychosocial theories, which emphasized the patient's voice as a critical part of the therapeutic process rather than treating them as mere objects [6]. This transition saw the rise of a more mutual engagement between doctors and patients, laying the groundwork for what we now refer to as patient-centered medicine [7]. The end of the 20th century witnessed an extensive body of literature advocating a patient-centered approach to medical care; this evolving perspective values the patient's input and promotes their active participation, effectively shifting from the traditional paternalistic model towards a more egalitarian and partnership-based approach [8]. In recent years, the management of chronic diseases has served as a prime example of patient-centered medicine, emphasizing empathy and equal power distribution through personalized treatment plans and leveraging shared decision-making aligned with patients' objectives, which appears to benefit adherence to treatment and health outcomes [9]. Nowadays, this patient-centered approach to health care is known as Patient-Centered Care and is generally recognized as an approach designed to accommodate individual patient needs, values, and beliefs, which is essential for providing safe, high-quality care, especially in light of an aging population and the rise in chronic diseases [10].

In light of the significant transformation of the doctor-patient relationship over the centuries, culminating in today's Patient-Centered Care, crucial questions arise regarding the ability of the patients, healthcare providers, and the healthcare system to adapt to this paradigm shift [11].

It is, therefore, essential to reflect on the adaptability of various actors in the healthcare field. For instance, the shift to a model that values patient input and active participation may initially seem overwhelming and unfamiliar to individuals who were born and grew up during the 20th century, an era where medical authority was dominant, and patients' voices were often overlooked. Similarly, questions arise for healthcare providers, particularly older ones who received their training around 30 years ago, who may find it challenging to adjust their practice and mindsets to this new approach. They were trained in a time when the paternalistic model was prevalent, where the doctor's authority was rarely questioned, and patients had a more passive role. Their experience was shaped under different premises, and their transition towards a more empathetic and participatory model might raise inevitable conflicts between them and their personal values. Additionally, it is vital to consider the broader healthcare system, which was largely constructed around the old paternalistic model, which was built to facilitate a more hierarchical, doctor-centric approach, with structures and protocols designed to fit this paradigm. However, with the shift towards patient-centered care, adjustments to these systems may be necessary.

1.1.2 Population aging, technological development, and the predictability of dying

The global trend of population aging is an influential factor that is significantly reshaping the landscape of healthcare access and utilization worldwide and within Switzerland [12]. According to the Federal Office of Public Health, Switzerland's population will age rapidly, with the number of residents aged 80 or over anticipated to more than double, increasing from 460,000 in 2020 to an expected 1.11 million by 2050 [13]. The escalating healthcare needs of this expanding older population, coupled with factors such as increased life expectancy and rapid medical advancements fueled by new technologies, are set to present unprecedented challenges to the healthcare system [12].

During the past 50 years, aside from the impact of the recent COVID-19 pandemic, life expectancy has persistently increased in most countries, even if the pace of growth has decelerated in the last decade [14]. In countries with lower mortality, the principal reason for the new heights in life expectancy was the decrease in death rates among older adults [15]. With factors such as advancements in healthcare, better living conditions, and healthier lifestyles, individuals are not only living longer, but they are also experiencing better health throughout their lives [16]. This question of living longer in better health is known as healthy aging and defined by the World Health Organization as the process of developing and maintaining the functional ability that enables well-being in older age [17]. Since chronic diseases are the leading cause of mortality worldwide, death has become more predictable [18]. This predictability allows older adults to manage and mitigate the course of such diseases more effectively [19].

In addition, the significant advancements in medical science, driven by the rapid growth of technological innovations, now present a wider spectrum of opportunities to prolong human life [20]. Modern medicine can manage diseases that used to be intractable and fatal while simultaneously improving the quality of life with previously unthinkable treatments [21]. For instance, the evolution of antiretroviral therapy for HIV/AIDS has transformed it from a near-certain death sentence in the 1980s to a manageable chronic condition today [22]. With consistent treatment, individuals with HIV can lead long, healthy lives and reduce the risk of transmitting the virus to others [23]. This remarkable progress is one example among others that shows the increased need for health decision-making, making it a fundamental aspect of modern healthcare.

Healthcare decisions are no longer confined to immediate responses to acute illnesses. Instead, they extend to a wide range of choices about the prevention, management, and treatment of chronic conditions, decisions that can profoundly affect individuals' health trajectories [24]. Health decision-making not only depends on the context in which individuals live, but it is also a continuous process that may evolve over time. For instance, individuals may need to decide when to begin certain preventative measures or treatments, which lifestyle modifications to adopt for managing a chronic condition, or even whether to opt for a surgical procedure that could improve their quality of life [25]. Ultimately, the complexity of these decisions is amplified by various patient-specific factors such as their education level, financial constraints, or social networks [26]. This highlights the crucial necessity for healthcare decisions to be well-informed and tailored to the individual's unique circumstances, preferences, and values.

As the number of older adults continues to rise, accompanied by improvements in life expectancy, health, and technological progress, new ethical questions are coming up around healthcare decision-making processes [27]. These changing circumstances raise important questions at different levels. For example, a key concern is whether older adults, on their own, have the necessary knowledge and understanding to make these increasingly complex health decisions. In addition, the role of caregivers, such as patients' relatives, in decision-making remains unclear. From the perspective of healthcare providers, there is uncertainty as to whether their training equips them to help their older patients navigate these complex decisions. Finally, there is a broader question of whether the existing healthcare system has effectively adjusted to these new challenges, ensuring it has the capacity to support patients and healthcare professionals in this new chapter of decision-making.

1.1.3 The need for more competencies related to decision-making

As individuals navigate the increasingly complex healthcare system, a fundamental component is their capacity to effectively handle health-related issues, often measured by the concept of health literacy. There are multiple definitions of health literacy, but for the purposes of this PhD thesis, the definition used is the one presented by the US Centers for Disease Control and Prevention, which states that personal health literacy is: "the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others" [28]. This definition was updated in August 2020 with the release of the U.S. government's Health People 2030 initiative [29]. It is important to note that the revised definitions of health literacy underscore individuals' capability to utilize health information rather than only understand it and prioritize making well-informed choices over merely appropriate ones.

Health literacy can be evaluated using subjective or objective methods, each having unique advantages and shortcomings [30]. Objective methods, like the Test of Functional Health Literacy in Adults (TOFHLA) or the National Assessment of Adult Literacy (NAAL), involve standardized tests gauging individuals' ability to perform specific tasks [31,32]. These tests are context-specific and require standardized conditions, which may place a significant burden on respondents [30]. Subjective measures, in contrast, ask individuals to rate their perceived difficulties with various health literacy tasks. These assessments are more adaptable, less stigmatizing, and quicker to administer than their objective counterparts. They also correlate closely with the concept of self-efficacy, an individual's belief in their ability to accomplish health literacy tasks, which influences health behaviors and healthcare use [33–35]. Given these attributes, subjective measures like the European Health Literacy Survey questionnaire (HLS-EU) or the Health Literacy Questionnaire (HLQ) are valuable in measuring individuals' abilities to seek, understand, evaluate, and utilize health-related information for informed judgments and decision-making in their daily lives at least as complementary measurements to more objective, test-based health literacy assessments [36].

Moreover, there has been a notable shift among policymakers, researchers, and practitioners in recent years from using functional health literacy measures to employing more comprehensive subjective tools [37]. The objective has been to broadly measure health literacy across the population to provide insight into individuals' degree of autonomy and empowerment within the healthcare system [38,39].

Health literacy is an essential factor that enables individuals to gain autonomy, enhance their satisfaction with healthcare, and aim for improved health and healthcare outcomes [40]. The importance of health literacy becomes evident when observing its impact on various aspects of health and well-being. Research has identified a distinct link between low health literacy levels and a decline in overall health, reduced use of preventive healthcare interventions, and significant obstacles in healthcare communication [36]. Furthermore, different sociodemographic groups, including those of advanced age, individuals with a background of migration, and those with a low perceived social status, tend to exhibit lower levels of health literacy [41]. In addition, health literacy can act as a strong predictor of health disparities among different individuals [42]. Factors such as age, language proficiency, education level, and socioeconomic status often play a role in these disparities [43]. Therefore, concentrating on improving health literacy among typically disadvantaged groups could serve not only to reduce these health disparities but also encourage a sense of empowerment among these individuals.

Measuring health literacy is also crucial for public health. It helps identify groups that are particularly vulnerable, allowing health systems to align their objectives towards improving accessibility, responsiveness, and solidarity, ensuring that everyone's needs are met [44]. In fact, the study of health literacy in the context of decision-making has provided major insights. For instance, recent research highlighted a potential link between personality traits and health literacy skills, revealing that individuals with greater openness seem to have better health literacy, whereas those with heightened neuroticism tend to struggle more [45]. Such results highlight the potential for public health policies to consider factors such as personality traits when developing strategies to enhance health literacy.

Findings from many studies have highlighted the importance of high levels of health literacy in the aging population at risk of chronic diseases as these skills influence how individuals perceive their health challenges, communicate with healthcare providers, and make more autonomous and informed medical decisions [46]. A recent Swiss study further revealed that older adults with multiple chronic conditions exhibit substantially lower health literacy levels than those without such conditions [47]. Strengthening health literacy in this vulnerable population subgroup could potentially lead to more effective self-management of health, reducing the adverse effects of inadequate health literacy on their health status and healthcare usage. Yet, the adequacy of conventional health literacy measures for end-of-life, a more challenging health context, remains unclear. The unique complexities and decisions inherent in end-of-life situations may require a more nuanced understanding and measurement of health literacy.

1.1.4 The end-of-life context

The societal and healthcare context surrounding the end of life have undergone significant transformations due to demographic shifts towards older populations and a growing tendency to medicalize aging, particularly towards the end of life [48]. These developments have brought about a certain predictability concerning the end of life, underscoring the increasing significance of considering personal preferences regarding end-of-life healthcare [49]. Therefore, considering individuals' unique wishes and needs during the end-of-life phase becomes increasingly crucial. The personalized approach to end-of-life care can potentially improve the quality of the remaining life, contribute to a more peaceful death, and possibly influence the bereavement processes of loved ones [49].

Switzerland, much like other high-income countries, sees most of its deaths among the older population. Most deaths are attributed to a limited number of causes: cardiovascular diseases, cancer, respiratory diseases, accidents, acts of violence, and dementia [50]. Since 2020, COVID-19 has become the third leading cause of death, following cardiovascular diseases and cancer [50]. In 2021, out of the total of 71,192 deaths recorded in the country, 25.8% involved individuals aged between 65 and 79 years old, while 61.6% concerned individuals aged 80 or older [51]. These deaths at older ages are typically not abrupt but instead the outcome of a slow progression of diseases and decreasing functional abilities over the final years of life [52]. Older adults often undergo one or multiple hospital admissions in the last phase of their life [53,54], and it is not uncommon for them to receive intensive medical care, which sometimes extends to treatments that may not serve a medically indicated purpose [55]. The escalating trend of medicalization at the end of life is reflected in the increasing proportion of older adults in Switzerland passing away in institutional settings rather than at home. Despite the preference of many Swiss residents to die at home [56], statistics reveal that 44% end their journey in a nursing home, 37% in a hospital, and only around 19% pass away at home or in other non-medical settings [57].

Decisions regarding end-of-life healthcare may encompass pain and symptom management measures, options to withhold or discontinue life-supporting treatments such as cardiopulmonary resuscitation, artificial nutrition and hydration, mechanical ventilation, or dialysis, and, notably in Switzerland, assisted suicide might also be considered [58,59]. Typically, these end-of-life choices are collaboratively made by the patients, if they are not cognitively impaired, and/or their family members or designated healthcare proxies, along with healthcare providers, following the principle of patient autonomy [60–62]. Determining factors for end-of-life care choices often include the patient's prognosis, the potential benefits and drawbacks of various treatments, and the patient's own values and care goals; this intricate decision-making process involves both patients and clinicians assessing the pros and cons, with patients primarily focusing on the potential impact on their quality and length of life, and physicians critically evaluating the medical suitability of the proposed treatments [63]. End-of-life decisions also include other personal factors determining the quality of life, such as perceived meaning in life, which is often associated with family, social relations, spirituality, religion, social commitment, and personal growth [64]. Many decisions can, in principle, be made when the situation arises but require the patients to have full mental capacity. Yet, more than half of the patients lack mental capacity at the time, which prevents them from expressing their wishes and making their own decisions [65].

As a result, advance care planning, a strategy involving structured conversations between healthcare providers, patients, and potentially their family members, can be established as foresight for a potential future decline in a patient's health [66]. The main purpose of this strategy is to ensure that medical treatments align with the patient's preferences, thus maintaining their quality of life throughout their healthcare journey and potentially leading to what the patient defines as a 'good death' [67–69]. Moreover, the decisions formulated through this process are usually documented in the form of advance directives [66].

Advance directives serve as a crucial tool in end-of-life planning, allowing individuals to express their healthcare preferences in written form, particularly about medical treatments they would consent to or refuse in situations where they may lack mental capacity [70]. They are not only a record of a patient's agreement or refusal to certain medical procedures but also a means to designate a healthcare proxy, a person entrusted with the responsibility to make medical decisions on the patient's behalf in the event they are unable to do so [70]. Advance directives are pivotal in safeguarding patient autonomy and self-determination, ensuring their medical treatments align with their personal wishes, thus helping preserve their quality of life [68,71]. They act as a crucial guide for families and healthcare specialists when confronted with difficult medical decisions, helping choose options that are most suitable and in line with the patient's documented preferences [72,73]. Furthermore, advance directives can mitigate the stress associated with surrogate medical decision-making, providing a sense of relief and clarity in challenging circumstances with probably important family conflicts around the appropriate course of action [74].

Even though advance directives and advance care planning are not always fully achieving their core objectives, such as enhancing a patient's quality of life or guaranteeing that end-of-life care aligns with the patient's personal preferences and care aims, it often successfully fulfill a number of secondary objectives. These objectives range from improving the quality of communication between the patient and physician, mitigating conflicts over decision-making, and fostering the documentation of both advance care planning and advance directives [75,76]. Additionally, the existence of advance directives can potentially shift care towards a non-hospital setting, intensify the emphasis on comfort care, and could play a part in reducing excessive treatment during end-of-life care [74].

Despite being legally recognized in the United States since 1991 under the Patients Self-Determination Act, it was not until 2013 that Switzerland introduced federal regulations pertaining to advance directives under the new adult protection law [77,78]. Advance directives play a pivotal role in advance care planning within the Swiss context. However, several obstacles stand in the way of realizing their full potential and effectiveness [77]. These challenges encompass low completion rates of advance directives, insufficient communication about their completion with family members, close friends, and healthcare providers, as well as inadequate awareness about their existence or location [77,79]. Improving these aspects could greatly enhance the overall efficacy and utility of advance directives in the healthcare landscape of Switzerland.

One prominent obstacle impeding the completion of advance directives and engagement in advance care planning is the potential lack of necessary competencies among individuals to handle the complexities inherent to health and healthcare decision-making in end-of-life contexts. These end-of-life decisions can be particularly intricate, often encompassing hypothetical scenarios that demand a delicate balance between quality and quantity of life. Moreover, the setting in which these decisions are made can pose additional challenges, as they frequently occur in emotionally charged situations with various family dynamics and interactions. Consequently, emphasizing individual competencies for managing end-of-life medical decisions is critical to ensuring individuals experience a respectful end-of-life process. Furthermore, enhancing these competencies can potentially alleviate the decision-making burden often shouldered by loved ones and healthcare providers.

1.2 Rationale behind the thesis

1.2.1 Importance of personal health literacy in relation to end-of-life issues

As previously introduced in this doctoral dissertation, the doctor-patient relationship has moved from a paternalistic, doctor-centered approach to the current patient-centered model that emphasizes the importance of patient participation. This shift has highlighted the need for patients, healthcare providers, and the healthcare system to adapt, particularly considering the aging population and technological advancements that are reshaping healthcare worldwide. As individuals live longer and healthier lives, healthcare decisions now also encompass chronic disease management and prevention. However, the increasing complexity of these decisions, largely due to technological evolution, raises critical questions about the readiness of individuals, healthcare professionals, and systems to face these challenges. Navigating this intricate healthcare landscape requires robust health literacy for sound decision-making, which is pivotal in ensuring patient autonomy and beneficial healthcare outcomes. Health literacy becomes indispensable for making complex health-related decisions with an aging population and increased life expectancy. However, traditional measures of health literacy may not suffice in end-of-life situations, necessitating a more nuanced understanding and assessment. Decisions about future health and medical care pose unique challenges, particularly toward the end of life.

Individuals often have to contemplate hypothetical scenarios and make decisions in advance regarding complex trade-offs between the quality and quantity of life in emotionally intense situations, which may involve challenging family dynamics and interactions. Although health literacy plays a pivotal role in disease prevention and healthcare decision-making, new measures of health literacy in relation to end-of-life issues are necessary. Any measure of health literacy related to end-of-life should consider the unique challenges of advance care planning and decision-making, such as planning for an uncertain future, dealing with questions of life and death, managing a high degree of risk and uncertainty, and overcoming substantial emotional hurdles, many of which are related to the familial and social context of dying.

1.2.2 Gaps in the existing literature

Despite the overall importance of end-of-life care, there is a surprising lack of research examining individuals' health literacy for this crucial life phase. The limited existing research indicates that patient understanding of end-of-life care choices is typically quite limited [80,81], suggesting that individuals might not have adequate skills to navigate end-of-life medical circumstances. A recent investigation involving the general population of adults aged 55 and older in Switzerland revealed significant knowledge gaps regarding end-of-life healthcare and planning options [82]. Many participants lacked understanding about surrogate decision-making and the legally binding nature of advance directives, and misconceptions about palliative care were widespread. The authors further argued that this lack of awareness might lead to poor end-of-life care choices and reduced patient involvement in decision-making. The researchers finally stressed the need to raise public awareness about end-of-life care options, especially among less informed groups, to ensure more patient-centered end-of-life care and to reduce the emotional burden of the dying process for patients and their families [82].

Other research exploring health literacy regarding end-of-life issues found that insufficient understanding in this area can result in decreased use of palliative care services, lesser completion of advance directives, suboptimal health conditions, diminished quality of life, and a rise in avoidable hospital admissions [83–85]. Two additional studies exploring concepts akin to health literacy related to end-of-life issues are the Death Literacy Index [86] and the ACP Engagement Survey [87].

The Death Literacy Index is the first global population-based tool for measuring death literacy, defined as: “the knowledge and practical skills that empower someone to make active choices around end-of-life options” [86]. This tool introduces a unique method for gauging societal understanding and comfort regarding end-of-life discussions and procedures. The survey instrument targets groups instead of individuals, emphasizing end-of-life support capabilities within communities or workplaces. Functioning as a population-based metric, the Death Literacy Index identifies current levels of death literacy and assesses the impact of initiatives intended to enhance this literacy. It encourages community dialogue, permits comparison with national averages, and aids in creating strategic plans to address identified gaps. Employed as either a one-time measurement or before and after implementing an initiative, it supports community development and the evaluation of intervention effectiveness [86].

The ACP Engagement Survey is a tool that measures an individual's engagement in advance care planning-related behaviors based on Social Cognitive Theory and Behaviour Change Theory [87]. It concentrates on four key aspects: engagement of decision-makers, considerations of quality of life, flexibility for decision-makers, and interactions with doctors. The survey assesses the extent of engagement in these behaviors through questions that address processes such as knowledge, contemplation, self-efficacy, readiness, and corresponding actions. Although the ACP Engagement Survey recognizes the role of family and surrogates, it is primarily designed to capture the individual's perspective [87]. This differentiates it from the Death Literacy Index, which primarily focuses on community-level responses to end-of-life issues. Both measures will be discussed in greater detail in the theoretical framework section of this doctoral thesis. However, it is important to emphasize that neither the Death Literacy Index nor the ACP Engagement Survey focuses particularly on an individual's ability to make medical decisions at the end of life.

To the best of our knowledge, no dedicated survey instrument specifically designed to measure health literacy related to end-of-life medical situations exists, particularly considering the unique decision-making challenges encountered during this phase compared to more conventional health and healthcare decision-making challenges.

1.3 Theoretical framework

1.3.1 Nutbeam's pioneering contribution to health literacy studies

As articulated by Nutbeam, health literacy extends beyond the traditional understanding of simply an individual's ability to comply with prescribed medical instructions [88]. Nutbeam's broader conception of health literacy is based on a three-level structure that depends on cognitive development, personal and social skills, and exposure to information. At the basic or functional level, health literacy implies having the necessary reading and writing skills for everyday tasks. The next stage is communicative or interactive health literacy, which demands more advanced cognitive and social literacy skills. These skills empower individuals to discern and understand various forms of communication and to extract and apply new information to evolving circumstances. The highest level, critical literacy, encompasses advanced cognitive abilities and social skills to analyze and use information critically. This level of health literacy allows individuals to have greater control over life events and situations. According to Nutbeam's model, the progression from basic to critical health literacy is not only a question of cognition but also depends on the nature of communication, personal and social skills, and individuals’ confidence in dealing with particular issues. Hence, health literacy is not only about transmitting health information but is tied to personal empowerment and autonomy [88].

Adapting Nutbeam's model of health literacy to end-of-life care, the three levels of health literacy would serve to guide the understanding and decision-making processes of patients, their families, and caregivers. This adaptation would assess individuals’ capacities to interact with healthcare providers, navigate complex health systems, and effectively manage health-related decisions at the end of life. From a theoretical point of view, functional health literacy would involve basic knowledge about end-of-life care options, including understanding terminal illness prognosis, the role of palliative care, and the utilization of health services in managing end-of-life symptoms. This first level would include traditional health education, focusing on improved knowledge about end-of-life care and compliance with recommended care plans. The second one, interactive health literacy, would progress to personal skill development within the context of end-of-life care. This could include communicating effectively with healthcare providers about care preferences, engaging in advance care planning, and developing a deeper understanding of the process of dying. Finally, the third level, critical health literacy, involves the cognitive and social skills needed to use the information and translate it into action. This might encompass individuals' decision-making regarding the end of life, potentially resulting in the drafting of advance directives or the designation of a surrogate to make medical decisions in the event of mental incapacity.

In conclusion, applying Nutbeam's health literacy model to end-of-life care could offer a comprehensive approach to educating individuals about end-of-life decisions while fostering personal empowerment and advocacy. By considering each level, healthcare providers could better tailor their communication and educational strategies to support individuals and families navigating the complexities of end-of-life care.

1.3.2 The Death Literacy Index

The Death Literacy Index is an innovative approach to understanding and evaluating the level of knowledge and comfort society has in discussing and managing end-of-life processes. This tool was created collaboratively by the Caring at End of Life research team from the School of Social Sciences at Western Sydney University, establishing itself as the first of its kind on a global scale [86]. It was designed based on qualitative research revealing that participating in end-of-life care could be both challenging and enlightening. Drawing insights from focus groups and interviews, where 308 participants shared their personal stories over six years, the team found that engaging in end-of-life caregiving empowered individuals to understand and navigate both the health and death systems literacy [89–91].

Designed as a 29-question survey, the instrument is divided into four subscales: Practical Knowledge, Experiential Knowledge, Factual Knowledge, and Community Knowledge [92]. Practical Knowledge involves individuals' comfort in discussing death, dying, and loss with others and their ability to provide hands-on care, with subcategories focusing on conversational support and physical caregiving tasks. Experiential Knowledge captures insights and skills gained from firsthand end-of-life experiences and encounters with death education. Factual Knowledge relates to individuals’ understanding of the death system, encompassing planning for end-of-life scenarios, caregiving, and post-death procedures. Lastly, Community

Knowledge pertains to individuals' awareness of end-of-life and grief support services in their community, including access to equipment, emotional aid, and local support groups.

The Death Literacy Index is primarily designed for group assessment rather than individual evaluation [92]. It offers insights into the capabilities of various groups, such as community members or employees in a workplace, regarding end-of-life support. It also enables researchers to determine current levels of death literacy across different populations, workplaces, and local communities. Moreover, it measures the impact of various local and wide-scale initiatives to improve death literacy. These insights are crucial as they provide a comprehensive understanding of what is needed to enhance the collective capacity to care for each other during end-of-life stages. One of the significant features of the Death Literacy Index is its flexibility. It can be utilized as a single-time measurement tool or applied before and after implementing an initiative to measure changes in death literacy. It also encourages community discussion about their collective death literacy, identifying areas of strength and those that need development. The Death Literacy Index further assists communities in planning and implementing strategies to improve their death literacy. By comparing results with the national average, communities can determine areas for improvement and develop targeted plans to address these gaps. This approach empowers community members to take action and reflect on the outcomes of their initiatives, providing valuable insights into whether the educational or community-based interventions have made a difference. Ultimately, the Death Literacy Index is a robust tool that harnesses a public health approach to palliative care, aiming to promote death literacy across various social strata and communities. It underscores the significance of ongoing dialogue and education in fostering an environment where discussions about death and dying are normalized and informed [92].

1.3.3 The ACP Engagement Survey

As explained earlier, the advance care planning process aims to ensure that medical care aligns with patient wishes. Although it traditionally focused on end-of-life decisions documented in advance directives, modern views regard this as limited and have redefined advance care planning as an ongoing process that adapts to an individual's changing values, necessitating regular communication with loved ones and healthcare providers [93,94]. Therefore, given the influence of behavior change theories on advance care planning and the need for a specific tool to evaluate all its aspects, the ACP Engagement Survey was created to provide a more comprehensive assessment [95].

The Advance Care Planning Engagement Survey was developed through a comprehensive approach that combined insights from prior research, expert consultations, and feedback from focus groups. This survey emphasized four central domains: Decision Makers, which focuses on identifying and documenting a surrogate for medical decisions; Quality of Life, which seeks to understand personal health values and document desired health outcomes; Flexibility, which determines how much freedom the surrogate has in making medical choices; and Asking Questions, aimed at preparing individuals to engage with doctors for informed medical decisions based on personal values. In each domain, the instrument integrates principles from behavior change theories, emphasizing knowledge ("How much do you know…"), contemplation ("How much have you thought about…", self-efficacy ("How confident are you…", and readiness ("How ready are you…"). It also includes questions on specific actions relevant to the four domains. Finally, all the questions can be divided into two main sections: Process Measures, which estimate these behavioral change factors, and Action Measures, which assess tangible steps taken in each domain. To ensure clarity, especially for older adults, the survey utilized plain language and larger text. Multiple reviews, interviews with older adults, and pilot tests further refined the survey's design and content. In the validation study of the initial ACP Engagement Survey, the authors concluded that their research on 50 older adults living in the United States demonstrated that individuals are not merely filling out forms but are actively discussing their preferences with family and healthcare providers. While other research exists on this advance care planning, their survey provides a deeper insight into behaviors and decision-making processes [95].

The original survey, though reliable, had 82 items and took an average of 49 minutes to complete, making it lengthy for common research and clinical use. Therefore, the authors did another study aiming to develop and validate shorter survey forms to evaluate the impact of advance care planning interventions more easily. Various validated versions exist, ranging from 82 items to just 4 items. Testing revealed that the concise versions could detect changes as effectively as the original one, making them suitable for research and clinical contexts. Choosing a survey version will depend on criteria such as how many resources are available, how much data needs to be gathered, and which parts of the survey are of interest [96,97].

The ACP Engagement Survey is thus a comprehensive tool developed to assess individual engagement in advance care planning, emphasizing both behavioral change factors and actionable steps across four central domains. The utility of the ACP Engagement Survey lies in its holistic approach to evaluating advance care planning. Instead of only documenting decisions, it delves deep into the process, examining individuals' knowledge, contemplation, self-efficacy, and readiness. By doing so, it captures the dynamic nature of advance care planning and can detect changes in behavior over time. This in-depth analysis provides insight into how and why individuals make certain end-of-life decisions, ensuring that care aligns more closely with their evolving values.

1.3.4 Residual gap: health literacy measures for end-of-life healthcare

End-of-life care is a pivotal phase in healthcare, where individuals deal with complex decisions, intense emotions, and complex navigation of medical and social systems [77,78]. To effectively support individuals during this stage, there is an exigent need to comprehend and address their health literacy, ensuring they are well-informed, empowered, and supported in their choices [98].

Research conducted in the United States suggested that health literacy is a key factor in improving end-of-life clinical outcomes [46]. The study found that patients often struggled to understand common medical terms, which can hinder end-of-life discussions, potentially preventing them from understanding crucial medical information for informed decision-making. Also, their emotional responses to certain terms could further obstruct these discussions. In addition, although most patients expressed a desire to be involved in end-of-life decision-making alongside healthcare providers and their loved ones, they often felt limited by the healthcare providers' readiness to communicate. Patients sensed healthcare providers' discomfort around the topic, felt that clear responses were lacking when end-of-life questions were asked, and believed doctors were reluctant to discuss the reality of dying. The hesitancy from healthcare providers sometimes even led patients to believe end-of-life discussions were unnecessary. Therefore, healthcare providers should consider the possibility of limited health literacy among patients and prioritize clear communication, including assessing a patient's health literacy level and avoiding complicated medical jargon. The study concluded that healthcare professionals and institutions can enhance patient-focused care by evaluating their health literacy and adapting their methods to support individual requirements [46].

Drawing from existing global end-of-life research, this doctoral thesis first introduced Nutbeam's Health Literacy framework, which defines health literacy skills as functional, interactive, and critical. When applied to end-of-life care, it illustrates how essential individuals' skills are, progressing from understanding basic information, such as specific medical terms, to effectively communicating with healthcare providers and, ultimately, making important decisions regarding end-of-life healthcare and its broader societal implications. Such a model underscores the increasing complexity and depth of competencies required as one navigates the end-of-life journey.

In addition, The Death Literacy Index offers another perspective, focusing not just on individuals' skills and knowledge regarding the death system but also on groups' collective societal approach and capability. This sheds light on broader societal constructs and beliefs about death and end-of-life care. Recognizing community strengths and areas for improvement can spark discussions and foster environments where death becomes a more normalized and informed topic of conversation.

Finally, the ACP Engagement Survey suggests another unique perspective by integrating principles from Social Cognitive Theory and Behaviour Change Theory, emphasizing knowledge, contemplation, self-efficacy, readiness, and action in individual engagement with advance care planning. This shift from viewing end-of-life decisions as static to recognizing them as an evolving discourse acknowledges that individual values and desires can change over time. Rather than solely focusing on understanding and documenting choices, this survey underscores the importance of continuous dialogue and engagement, highlighting the fluidity and complexity of individuals' desires and values at the end of life.

The different approaches highlight the importance of individuals’ skills when dealing with end-of-life care situations. Personal health literacy related to end-of-life is unique, and its significance is multi-fold. Unlike other phases in healthcare where patients might recover or continue treatments indefinitely, end-of-life care is a definitive stage. Decisions made here resonate beyond the patient, influencing families, caregivers, and the community. Inaccurate or incomplete understanding can lead to choices that may not truly reflect an individual's wishes, potentially leading to regret, grief, or conflict among loved ones. Given the weight of these decisions and their impact, it is essential to prioritize new complementary health literacy measures tailored specifically for end-of-life care.

1.4 Research aims

1.4.1 Outline of each research question

This PhD thesis offers a detailed analysis of end-of-life health literacy among older adults in Switzerland. The specific objectives are described across five distinct studies, each detailed in research articles accepted in or submitted to internationally recognized, peer-reviewed scientific journals. The subsequent research questions are structured in alignment with this approach.

- Study I: “What is the prevalence of health literacy levels among older adults in Switzerland, and how is health literacy associated with specific sociodemographic factors?” This study investigates the health literacy levels of adults aged 58 and older in Switzerland. The research explores the correlation between individual characteristics such as gender, education, financial situation, self-assessed health, and health literacy, aiming to discern the prevalence and potential health inequalities among the older Swiss population (*published article I*).

- Study II: “How accurately do older adults in Switzerland perceive end-of-life medical situations, and how are these perceptions correlated with sociodemographic characteristics?” The research analyzes the perceptions and knowledge of older Swiss adults concerning end-of-life medical situations. The emphasis is on understanding the heterogeneity and accuracy of these perceptions for different end-of-life medical situations, including questions on, for instance, the success of cardiopulmonary resuscitation, prevalence of dementia, and pain management. The associations with individuals’ factors such as gender, age, and regional characteristics on these perceptions are also examined (*published article II*).

- Study III: “Is there a correlation between older adults' knowledge of cardiopulmonary resuscitation survival rates and their preferences to receive cardiopulmonary resuscitation during medical emergencies?” This study delves into older Swiss adults' understanding of cardiopulmonary resuscitation success rates. It analyzes whether misconceptions about cardiopulmonary resuscitation survival rates are associated with their decisions on whether or not they would prefer to receive cardiopulmonary resuscitation after a cardiac arrest (*accepted article III*).

- Study IV: “Can the Subjective End-of-life Health Literacy Scale (S-EOL-HLS) reliably measure the self-assessed competencies of older adults in Switzerland in dealing with end-of-life medical situations?” This research introduces the S-EOL-HLS, a tool designed to measure individuals’ self-assessed competencies to deal with end-of-life medical situations. It evaluates this scale's validity, reliability, and consistency, comparing it with the established European Health Literacy Survey questionnaire (*published article IV*).

- Study V: “How is end-of-life health literacy associated with the knowledge, attitudes, and behaviors of older adults in Switzerland toward advanced care planning ?” This study seeks to understand the link between end-of-life health literacy and individuals' knowledge and attitudes toward advance care planning. It examines how end-of-life health literacy levels relate to an individual's knowledge about end-of-life situations, discussions about end-of-life wishes, completion of advance directives, and designation of a surrogate to make medical decisions. The aim is to underscore the pivotal role of end-of-life health literacy in shaping end-of-life care planning and decisions (*submitted article V*).

1.4.2 The overall goals of the thesis

The transition from a provider-centered to a patient-centered healthcare model, intensified by an aging population and technological advancements, accentuates individuals' need to develop their health literacy skills, particularly for intricate end-of-life decisions. The overall goal of this PhD thesis is to provide an in-depth public health perspective on end-of-life health literacy. Initially, the research delves into understanding health literacy and identifies potential health-related disparities among older adults in Switzerland. Recognizing the significance of health literacy, the focus narrows to older adults' comprehension and perceptions of specific end-of-life medical scenarios, aiming to identify knowledge gaps that may impact crucial end-of-life care decisions. Furthermore, the study explores potential misconceptions tied to individuals' end-of-life treatment preferences and their potential influence on decisions. Then, this research aims to introduce and validate a novel instrument tailored to measure older adults' skills in handling end-of-life situations. This innovative instrument aims to enhance older adults' end-of-life care communication and decisions and supports its potential broader application to ensure goal-concordant care. Ultimately, the research seeks to comprehend the larger repercussions of this new end-of-life health literacy tool on knowledge and attitudes toward advance care planning, bridging the gap between theoretical knowledge and actionable insights that could shape health outcomes.

1.5 Data sources and methodological approach

1.5.1 The Survey of Health, Ageing, and Retirement in Europe

This PhD thesis uses data from the Survey of Health, Ageing and Retirement in Europe (SHARE) to examine the end-of-life health literacy of older adults in Switzerland.

SHARE is an extensive research platform that compiles micro-level data from older individuals across 27 European countries and Israel [99]. Initiated in 2004, this longitudinal study draws random representative samples of older individuals from each participating country. It delves into the nuanced interplay of health, socio-economic status, and social and family networks. SHARE collects data from Europeans aged 50 and above and their partners every two years using Computer-Assisted Personal Interviews (CAPI). During these interviews, a range of information is gathered: details about participants' mental and physical health (including biomarkers and functional tests), cognitive abilities, and healthcare utilization; socioeconomic data such as demographics, employment, pensions, computer skills, household incomes, expenditure, assets, housing, activities, and future expectations; and insights into their social or family ties, social support, and well-being. Waves 3 and 7 additionally provided life history data, capturing elements like childhood conditions and histories related to family, employment, health, and residence.

With the onset of the COVID-19 pandemic, SHARE introduced two Computer Assisted Telephone Interviews (CATI) between June and August 2020 and 2021. These Corona Surveys focused on areas affected by the pandemic, exploring changes in health behavior, infections, economic and work status, and social networks.

1.5.2 Study design and sample

Switzerland has actively participated in SHARE since its beginning and has consistently been involved in data collection every two years. Interviews are conducted face-to-face in French, German, and Italian. The Swiss SHARE study secured ethical approval from the Canton of Vaud, Switzerland Ethics Committee, in March 2014, with approval number 66/14. For each survey round, respondents consent to participate in the SHARE study twice: first, when they agree to schedule an interview following a phone call, and second, when they attend the face-to-face interview. Besides the core SHARE interviews, each country can add a country-specific self-administered paper-and-pencil questionnaire administered at the end of the in-person interviews. In Switzerland, the multidisciplinary SHARE team developed two end-of-life questionnaires.

The 2015 questionnaire, collected during Wave 6, explored various end-of-life planning facets such as elaborating living wills, assignment of general power-of-attorney, and organ donation card possession. It also surveyed advance care planning, detailing aspects like advance directives and healthcare proxies. This survey presented various end-of-life preferences, covering 23 specific medical and non-medical end-of-life issues. Moreover, it investigated end-of-life communication and assessed participants' knowledge about pivotal end-of-life concepts in Switzerland. Other sections addressed perceived end-of-life restrictions, preferred location of death, views on assisted suicide, and trust levels in key end-of-life decision-making institutions.

The second end-of-life questionnaire, collected during Wave 8 between the end of 2019 and early 2020 (pre-COVID-19 first Wave), maintained continuity with its 2015 predecessor to have a longitudinal perspective. It re-evaluated many areas covered in the earlier survey and introduced new dimensions. For instance, it delved deeper into older adults' perceptions and understanding of various end-of-life medical situations in Switzerland. It examined preferences linked to the official advance directive template by the Swiss Medical Association. The survey also investigated further the dynamics of spousal communication regarding end-of-life preferences, aiming to offer a layered understanding of such interactions. To align with global aging study trends, it incorporated components from the European Health Literacy Survey (HLS-EU), notably featuring the short health literacy scale (HLS-EU-Q16). A novel end-of-life health literacy tool, the S-EOL-HLS, was also introduced and subsequently validated within this PhD thesis.

The dataset used in the various studies encompassed in this PhD thesis combines data from SHARE's internationally harmonized interviews, such as sociodemographic variables, with information from the national self-administered paper-and-pencil questionnaires on end-of-life issues from Wave 8. In total, 2,005 Swiss respondents participated in Wave 8 of SHARE [100]. Among them, 1,891 completed the Swiss self-administered questionnaire on end-of-life issues, resulting in a cooperation rate of 94.3%. While the objective of SHARE is to provide nationally representative data on individuals aged 50 and above, along with their partners living in the same household, the Swiss SHARE sample from Wave 8 (2019/2020) has not been refreshed since 2011 and no longer encompasses adults aged 50 to 57 in Switzerland. Consequently, to ensure the representativeness of Swiss citizens in studies where necessary, the sample only includes respondents aged 58 and older. Lastly, after narrowing down to respondents without missing information on at least one item used in the analysis, the total number of respondents included ranges from 1,217 to 1,625, depending on the study's research question.

1.5.3 Statistical analysis

Regarding the statistical methods employed across various studies, the relative frequencies of overall respondents and specific groups for each variable in the analytical sample were determined through weighted estimations and/or unweighted count numbers based on the research question at hand. The cross-sectional weights from the SHARE dataset ensured accurate descriptive statistics representing the intended population. These weights address challenges like nonresponse and sample attrition. The calibration technique that SHARE adopts for these weights is consistent with the method proposed by Deville and Särndal (1992) [101]. Pearson's chi-squared tests (X^2) were employed to contrast bivariate associations between the outcome and the independent variables. Moreover, several regression models were used to assess partial associations between various outcomes and independent variables—often controlling for participants' sociodemographic characteristics. These included models such as Ordinary Least Square (OLS), probit, and multivariable ordered probit. Examining these associations through diverse statistical models ensured a consistency check for the estimates. Adjustments were made to the estimated standard errors to factor in potential data interdependencies, given that partners from the same household could yield similar responses. The "cluster" command in STATA was engaged to align these regressions at the household level. All calculations were conducted using the STATA/SE 17.0 software (STATA Corporation, College Station, TX). To validate the S-EOL-HLS, both exploratory and confirmatory factor analyses were employed to assess the scale's construct validity. These analytical processes were carried out using the Psych version 2.2.9 and Lavaan 0.6-12 software packages in R version 4.1.2.

1.6 Thesis list of scientific papers

This doctoral dissertation comprises five scientific articles. These articles have been submitted to internationally renowned scientific journals that defend rigorous peer-review standards. A detailed list of these articles is provided below.

I. Meier C, Vilpert S, Borrat-Besson C, Jox RJ, Maurer J; *Health literacy among older adults in Switzerland: cross-sectional evidence from a nationally representative population-based observational study*. Swiss Med Wkly. 2022 Apr 5. (Available from: https://smw.ch/article/doi/smw.2022.w30158)

II. Meier C, Vilpert S, Borasio GD, Maurer J, Jox RJ; Perceptions and Knowledge Regarding Medical Situations at the End of Life among Older Adults in Switzerland. J Palliat Med. 2022 Jun 29; (Available from: https://www.liebertpub.com/doi/10.1089/jpm.2022.0057)

III. Meier C, Vilpert S, Wieczorek M, Borasio GD, Jox RJ, Maurer J; *Overestimation of success rates of cardiopulmonary resuscitation is associated with higher preferences to be resuscitated: evidence from a national survey of older adults in Switzerland.* (*Accepted for publication to the Medical Decision Making journal*).

IV. Meier C, Vilpert S, Wieczorek M, Borrat-Besson C, Jox RJ, Maurer J; *Development and validation of a subjective end-of-life health literacy.* (Available from: https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0292367).

V. Meier C, Vilpert S, Wieczorek M, Borrat-Besson C, Borasio GD, Jox RJ, Maurer J; End-*of-life health literacy, knowledge, and attitudes toward advance care planning among older adults in Switzerland.* (Under review BMJ Public Health*).*

2. Brief summary of the main results

This section summarizes the main results extracted from each of the five scientific papers from the PhD thesis.

I. Health literacy among older adults in Switzerland: cross-sectional evidence from a nationally representative population-based observational study

In Switzerland, among adults aged 58 and older, 6.8% exhibited inadequate health literacy, 24.6% had problematic health literacy, and 68.6% showed sufficient health literacy. Factors such as gender, education level, economic situation, and self-rated health were significantly associated with health literacy. Women, individuals with higher education, those experiencing fewer financial challenges, and those with better self-assessments of their health tended to have better health literacy levels. As a result, about a third of older Swiss citizens face difficulties managing health-related issues, especially those with lower education, financial difficulties, and poorer self-perceived health. The study suggests the adoption of simplified health tools, better patient communication, and promoting lifelong learning to improve health literacy and address related social health inequalities.

II. Perceptions and knowledge regarding medical situations at the end of life among older adults in Switzerland.

Older adults in Switzerland often hold inaccurate perceptions about medical end-of-life situations. They tend to overestimate the success of treatments like cardiopulmonary resuscitation and certain chemotherapies and the benefits of hospital admission for patients with advanced dementia. Additionally, they underestimate the effectiveness of pain management during the dying phase. Less than 28% accurately assessed the likelihood of dying in different locations such as homes or hospitals. Men and individuals with financial difficulties had more misconceptions, while adults aged 75+ and those from the German-speaking region had more accurate views. This highlights a need for improved knowledge about end-of-life realities in Switzerland.

III. Overestimation of success rates of cardiopulmonary resuscitation is associated with higher preferences to be resuscitated: evidence from a national survey of older adults in Switzerland.

In Switzerland, from a population-based sample of adults aged 58 and older, only 9.3% accurately understood the survival rates of cardiopulmonary resuscitation performed outside of a hospital. However, 65.2% preferred to be resuscitated if they had a cardiac arrest. Those who correctly understood the cardiopulmonary resuscitation survival rates were significantly more inclined to prefer not to be resuscitated. The study concludes that correcting misconceptions about cardiopulmonary resuscitation's success rates might lead older adults to reconsider their preferences regarding the treatment.

IV. Development and validation of a subjective end-of-life health literacy scale.

This study introduced and validated the Subjective End-Of-Life Health Literacy Scale (S-EOL-HLS) to measure older adults' self-perceived ability to understand and make decisions about end-of-life medical situations. The scale, tested on participants, assessed understanding of medical jargon, pre-determining medical treatments for end-of-life care, and communicating these decisions. The S-EOL-HLS showed a reliable three-factor model. When compared to a general health literacy questionnaire, those with higher scores on the S-EOL-HLS had more favorable views on end-of-life care planning. This instrument demonstrated consistency and reliability, making it a valuable tool for surveys targeting older adults.

V. End-of-life health literacy, knowledge, and attitudes toward advance care planning among older adults in Switzerland.

This study examined the association between end-of-life health literacy and individuals' knowledge and attitudes toward advance care planning in adults aged 58+ in Switzerland. It was found that higher end-of-life health literacy correlated with better knowledge of end-of-life situations and a greater likelihood of discussing end-of-life preferences, completing advance directives, and designating a healthcare proxy. The study also identified two important end-of-life health literacy dimensions with regard to end-of-life knowledge and attitudes toward advance care planning: interactive and critical. The interactive component was associated with end-of-life knowledge and planning attitudes, while the critical component was mainly associated with establishing advance directives and choosing a healthcare proxy. The research concludes that enhancing end-of-life health literacy could positively influence individuals' engagement in advance care planning, suggesting a need for public health policies to bolster these skills.

3. Discussion

3.1 Finding overview

As highlighted by the different studies presented in this doctoral thesis, in Switzerland, a significant portion of older adults faces challenges regarding their personal health literacy. About one-third of respondents report struggling with managing health-related issues, with important factors such as gender, education, financial difficulties, and self-perception of health emerging as pivotal determinants. In addition, misunderstandings about end-of-life medical situations are prevalent among older adults, especially regarding the efficacy of treatments such as cardiopulmonary resuscitation. In fact, only 9.3% of respondents accurately understood the survival rates of out-of-hospital cardiopulmonary resuscitation for a 70-year-old. Those who correctly understood the cardiopulmonary resuscitation survival rates were significantly more inclined to prefer not to be resuscitated. Moreover, the introduction of the S-EOL-HLS offers a promising tool to measure older adults' self-perceived end-of-life health literacy skills, which are central to decision-making at the end of life. Individuals scoring higher on this scale have better end-of-life knowledge and a more positive attitude toward advance care planning. More precisely, improved end-of-life health literacy correlates with informed actions, such as discussing end-of-life preferences, completing advance directives, and designating a surrogate for medical decisions. These findings emphasize the need for Switzerland to enhance public health policies that bolster end-of-life health literacy, ensure clear medical communication concerning end-of-life wishes, and stress the importance of advance care planning. Developing end-of-life health literacy skills among older adults is crucial for making better-informed choices and potentially improving end-of-life healthcare quality in Switzerland.

3.2 Implications for public health

To empower individuals to make better-informed decisions and reduce health inequalities that could emerge from a lack of end-of-life health literacy skills, it is essential to pursue new types of public health policies. Current health literacy movements predominantly follow a top-down approach, designing interventions to aid those with low health literacy in understanding and effectively utilizing health information [102]. Instead, emphasis should be placed on the notion of critical health literacy, first introduced by Nutbeam, which assists individuals in understanding and acting upon health matters by critically considering social health determinants [88]. Despite its use in health discourse for over 20 years, critical health literacy has lacked a clear definition and robust theoretical grounding. In a recent article, a refined definition was presented, emphasizing the dual components of reflection and action. Reflection involves critically analyzing socio-cultural factors impacting health, while action focuses on the capability to modify these factors. The authors argue that for critical health literacy to be effective, reflection and action must interplay: reflection without action might lead to mere intellectual recognition, whereas action without reflection can result in aimless activism. Current approaches emphasize the need to understand social and cultural conditions to address health inequalities [103].

Regarding the end-of-life context, individuals' end-of-life health literacy skills are essential for both reflection and action. With the transition to a patient-centered healthcare model, amplified by an aging population and technological advancements, individuals increasingly need to reflect and adopt a critical attitude towards the socio-cultural realities of what it means to end their lives in Switzerland. Individuals' end-of-life health literacy skills could empower them to have accurate representations of different end-of-life medical situations, to question their own end-of-life wishes, and to understand the healthcare system along with the importance of planning for their end-of-life. As for action, individuals need the appropriate end-of-life health literacy skills to make informed decisions and communicate these decisions with whomever they choose, using their preferred method of communication. Everyone has a different level of end-of-life health literacy skills, evolving throughout their lives and influenced by numerous personal factors such as culture, education, life experiences, religion, and gender [104]. The variety of sources from which individuals acquire end-of-life health literacy skills highlights the challenge of targeting specific aspects to enhance these skills.

In a recent study conducted in Sweden, the use of the DöBra cards, a tool designed to facilitate end-of-life conversations among older adults, appeared to be a good example of how to build competencies to deal with end-of-life care and communication [105]. The DöBra cards aim to promote reflection and discussion about end-of-life values and preferences. Based on feedback from healthcare providers, the cards proved useful in shaping the content of conversations and facilitated better communication about future care plans, aligning with older adults' care goals. The DöBra cards offer a structured yet flexible approach, allowing for deep reflection on end-of-life values beyond medical care. The authors further explained that the cards' adaptability and physical format encouraged active participation and were even useful with residents having mild cognitive decline [105]. Another example from the Netherlands showed that to stimulate older adults' interest and guide them through the complexity of end-of-life medical situations, inviting them to information sessions about end-of-life healthcare led by general practitioners can positively impact individuals' engagement in advance care planning [106]. The authors also clarified that while this method primarily appeals to older individuals with a pre-existing interest in the subject, it seems to promote advance care planning effectively. Moreover, a Swiss study conducted across four palliative care units, aiming to understand the factors influencing patients' decisions to complete advance directives, found that regional, cultural, and linguistic differences played a role in these decisions [107]. The location of the palliative care units emerged as a predictor of advance directives completion. In the study, while many patients expressed a preference for active participation in decision-making, few communicated their wishes to their relatives or documented them formally. Additionally, the authors argued that the attitudes of healthcare professionals could have deterred patients from discussing future complications or completing advance directives. Overall, while patients trust their physicians and aspire for shared decision-making, a notable gap exists in communicating end-of-life preferences [107]. This highlights the necessity of tailored approaches considering regional specificities and healthcare professionals' perspectives to promote end-of-life health literacy in individuals and foster shared decision-making. Building on the importance of professional competencies in this domain, the European Association for Palliative Care has published a White Paper [108]. This document outlines the fundamental competencies required of health and social care professionals working in palliative care. Their goal is to standardize educational protocols and to consistently deliver high-quality care to patients and families, irrespective of the healthcare environment they encounter within Europe [108].

An alternative approach to support individuals' end-of-life health literacy and their attitudes towards the end-of-life could be through their social network. A qualitative study from Belgium explored the behaviors and factors influencing family caregivers when initiating palliative care for their loved ones. The research identified three primary behaviors: discussing palliative care, seeking and understanding palliative care information, and organizing and coordinating care. Several factors influenced these behaviors, including attitudes towards palliative care, awareness of the patient's health condition, gaps in understanding about palliative care, and social influences. One significant finding was that many associate palliative care with end-of-life scenarios, often perceiving it as a last resort, which may delay its introduction. The study produced a preliminary behavioral model that can be utilized to develop interventions for better-supporting family carers in their decision-making around palliative care [109].

On a broader level, promoting personal end-of-life experiences in the media could encourage individuals to reflect on and improve their end-of-life health literacy skills. For instance, a U.S. study investigated the impact of media coverage on advance care planning, focusing on the case of a woman in a persistent vegetative state whose end-of-life decision became a major media event. Although individuals with higher literacy and education levels were more likely to have heard about this woman's situation, many respondents reported that the story prompted them to consider and discuss their own end-of-life preferences. Specifically, 61% felt more certain about their medical care wishes, 66% discussed their preferences with family or friends, and 37% expressed an interest in completing an advance directive. This highlights the significant role the media can play in disseminating health-related information and shaping personal health decisions [110]. Another intervention that could trigger individuals' interest in end-of-life issues and bolster their skills is establishing a national day or week dedicated to widespread discussion on the topic. Such events have been developed worldwide, notably in the United Kingdom with the "Dying Matters Awareness Week." Every year, the country uses this week as an opportunity to encourage communities to engage in conversations about death and dying [111]. In parallel, other initiatives, such as creating a specific website or an app to offer more information about end-of-life care, can enhance individuals' end-of-life health literacy. For example, a recent study conducted at the Geneva University Hospitals in Switzerland introduced a new tool for aligning end-of-life care objectives [112]. The pioneering French-language mobile app named "Accordons-nous," still under development, is centered on advance care planning and designed to initiate a personal reflection on the subject, begin a dialogue with loved ones and medical staff, and draft potential advance directives using a simple, downloadable questionnaire that can be modified at any time [112].

Finally, another potential improvement within the broader healthcare framework would be the implementation of a "Personal Healthcare Guide" for individuals aged 50 and above. Drawing inspiration from the vaccination booklets available for children, this guide could help consolidate individuals’ health and end-of-life care preferences, ensuring they align with their personal values, desires, and objectives. Making this a mandatory provision could catalyze a paradigm shift in the healthcare system, nudging it towards a model with an increased focus on public health. To facilitate this, a compulsory visit to the general practitioner upon turning 50 could emphasize the significance of proactive health management, fostering an environment that supports health literacy and prepares individuals for pivotal end-of-life choices. For healthcare professionals, this guide would offer deeper insights into their patients, fostering pivotal end-of-life discussions and aiding in maintaining such records. The "Personal Healthcare Guide" could also contain other personal information that individuals think is important, especially if they were to become mentally incapacitated. This might encompass details such as the language they understand, any disabilities (e.g., hearing impairments), cultural background, religious beliefs, life experiences, gender, or sexual orientation. Such an initiative would underscore the value of patient-centric care, enabling healthcare providers to tailor their communication based on individual patient profiles. Furthermore, it would also prompt the healthcare system to prioritize the aging population’s needs and focus on strengthening their end-of-life health literacy skills to ensure that everyone ends their life with the respect they deserve.

3.3 Recommendations for future research

As the validation study of the S-EOL-HLS showed, further research could explore the instrument's utility, designed to measure individuals' self-assessed competencies to deal with end-of-life medical situations. This tool could help determine if those with lower end-of-life health literacy are less likely to obtain care that aligns with their values, preferences, and goals. Active steps towards end-of-life goal-concordant care could involve discussions with medical professionals, completing advance care planning documents, and communicating wishes to surrogates for medical decisions or loved ones. Evaluating the relationship between end-of-life health literacy and goal-concordant care could offer vital insights to support the decision-making process.

In addition, the dynamic nature of end-of-life health literacy is another potential research focus. Tracking its evolution over time, particularly after major life events such as a critical diagnosis for an individual or their loved ones, can uncover patterns and guide the development of interventions. The S-EOL-HLS instrument can help evaluate the efficacy of initiatives focusing on enhancing end-of-life health literacy, such as educational courses and communication efforts, by comparing individuals' end-of-life health literacy levels before and after these interventions. Future research should also delve into the differential impact of end-of-life health literacy across various demographic groups, considering cultural and socioeconomic disparities.

While it is essential to consider individuals' subjective evaluations when assessing their understanding of end-of-life care options, there is an equally pressing need for objective measures of end-of-life health literacy. These objective measures can offer a standardized evaluation, providing a comprehensive and balanced view of an individual's knowledge and understanding of end-of-life care ensuring that both personal perceptions and evidence-based standards are taken into account.

Finally, while the S-EOL-HLS focuses on individual end-of-life healthcare decisions, it could also be interesting to extend the tool further and assess the ability to make surrogate decisions for others, as individuals often need to decide on behalf of family members. As the field advances, continuously exploring factors related to individuals' end-of-life health literacy is crucial to ensure a dignified end-of-life experience for patients, families, and healthcare providers.

3.4 Study limitations

Our research encountered various limitations across studies. Primarily, the use of subjective tools, such as the HLS-EU-Q16 and S-EOL-HLS questionnaires, might incorporate reporting biases, potentially leading respondents to overstate or understate their skills. Despite this, the HLS-EU-Q16’s short version offers quick responses for older adults and remains a validated instrument. The S-EOL-HLS, although extensive, only encompasses a fraction of end-of-life health literacy skills, which might raise concerns about comprehensiveness and clinical relevance. Regarding our measure of end-of-life knowledge, using qualitative and quantitative labels in questions might have led to confusion among some respondents, potentially impacting the quality of their responses. Sample selection bias remains a recurring concern, with issues such as attrition potentially excluding the very old or those with significant health issues. While the study SHARE aims for an accurate representation of Switzerland’s older population, there may be a possibility of non-inclusion of certain vulnerable groups. Additionally, challenges in survey administration, especially in nursing homes, might have left out some respondents. Yet, the high response rate and consistent respondent characteristics in the studies offer a degree of confidence in the results. Lastly, our research design does not allow us to establish causality, and validating the S-EOL-HLS tool across the three Swiss national languages was not feasible, though preliminary analyses did show consistency for German and French versions.

3.5 Reflections and conclusions

This doctoral thesis has shed light on the pressing concerns surrounding end-of-life health literacy among older adults in Switzerland. It has also underscored the essential role of including the humanities in healthcare, establishing a pathway for respectful and compassionate relationships between healthcare providers, patients, and their loved ones. Switzerland should prioritize public health policies that emphasize clear medical communication around end-of-life medical situations and promote the importance of strengthening individuals' end-of-life health literacy skills. In doing so, the nation can ensure that its older population has the necessary knowledge and tools to make well-informed decisions, potentially leading to a dignified and respectful end-of-life experience. Future research should continuously refine and expand end-of-life health literacy tools and interventions available, ensuring that every individual receives the end-of-life quality of care they deserve.

4. Articles

4.1 Article I

Title: Health literacy among older adults in Switzerland: cross-sectional evidence from a nationally representative population-based observational study.

Authors: Clément Meier, Dr. Sarah Vilpert, Dr. Carmen Borrat-Besson, Prof. Ralf J. Jox and Prof. Jürgen Maurer

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Health literacy among older adults in Switzerland: cross-sectional evidence from a nationally representative population-based observational study

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Summary

BACKGROUND AND AIM: Despite being widely regarded as a major cause of health inequalities, little is known regarding health literacy and its association with certain personal characteristics among older adults in Switzerland. To fill this gap, this study assesses health literacy and its associations with individuals' social, regional, and health characteristics in a nationally representative sample of adults aged 58 years and older in Switzerland.

METHOD: We use data of 1,625 respondents from a paper-and-pencil self-completion questionnaire (cooperation rate: 94.3%) that was administered as part of wave 8 (2019/2020) of the Survey of Health, Ageing and Retirement in Europe (SHARE) in Switzerland. Health literacy is measured using the short version of the European Health Literacy Survey questionnaire (HLS-EU-Q16). The scale includes 16 items whose dichotomised responses allow the construction of different indices and sub-indices aimed at measuring various aspects of health literacy. We use multivariable regressions to explore how respondents' sociodemographic characteristics are independently associated with health literacy.

RESULTS: Overall, 6.8% of the respondents had inadequate health literacy, 24.6% problematic health literacy, and 68.6% sufficient health literacy. There were significant associations between health literacy and individuals' gender, education, economic situation, and self-rated health. Women had higher levels of health literacy than men ($p < 0.001$). Moreover, a higher education level ($p < 0.001$), fewer financial difficulties ($p<0.01$), and higher self-rated health ($p < 0.001$) were positively correlated with adequate/higher levels of health literacy.

CONCLUSION: One-third of older citizens have difficulties managing health-related issues in Switzerland. Individuals with low education, financial difficulties, and bad self-rated health are particularly at risk of being disadvantaged due to their inadequate health literacy level. These findings call for targeted interventions, such as using simplified health or eHealth information tools, improved patient-provider communication and shared decision-making, promoting lifelong learnings activities and health literacy screening for older patients to increase low health literacy and mitigate its consequences, thereby alleviating remaining social health inequalities in the Swiss population.

Introduction

Individuals differ in their ability to deal with health-related issues, which influences their health-related behaviour and decisions. A common measure of skills regarding health-related issues is health literacy. Health literacy refers to "the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others" [1]. Health literacy skills enable individuals to engage in behaviour beneficial to their health, such as adopting a healthier lifestyle, seeking more appropriate healthcare services, and empowering them in the event of illness [2].

During the past few years, policymakers, researchers, and practitioners have moved the growing attention from functional health literacy measures to broader subjective instruments [3]. The focus was on comprehensively measuring health literacy in the general population to capture individuals' competencies to seek, understand, appraise and use health-related information for making judgments and decisions in everyday life [4]. This approach allows measuring the autonomy and empowerment of citizens regarding the health care system [2]. Recent studies implementing this concept found that low health literacy levels are associated with poor health status, lower use of preventive healthcare interventions, and key barriers to medical conversations

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[5]. Low health literacy is associated with advanced age, a migration background, and low self-assessed social status [6]. Moreover, varying health literacy is a strong predictor of health disparities between individuals, related to factors such as age, language, education, and socioeconomic status [7, 8]. Therefore, improving health literacy in disadvantaged groups may contribute to reducing social inequalities in health and raising patient empowerment.

At the population level, measuring health literacy is an instrument of public health that allows identifying vulnerable sub-groups to follow the main goals of the health system regarding accessibility, responsiveness, and solidarity [9].

Switzerland aims to pursue these goals to give all citizens equal opportunities for good health. Yet, implementing health equity remains a challenge as several socially disadvantaged groups face challenges due to language, origin, social status, or education level [10]. The Swiss Federal Office of Public Health (FOPH) aims to promote health equity by creating effective policies and interventions targeted at these socially disadvantaged population groups. The FOPH recently conducted a national health literacy survey on citizens over the age of 15; the results of the study from 2020 revealed that health literacy in Switzerland is generally poor, with approximately 38% of the population having problematic health literacy. However, the problem is not that deep as only 11% of respondents displayed inadequate health literacy [11]. This study also indicated that low health literacy was associated with poor financial means, lower education level and lower health status. The FOPH study focused on the entire population; however, health literacy skills are particularly relevant in aging populations with large chronic and severe diseases burdens. Health literacy influences how older individuals perceive their health problems, communicate with health professionals and make medical decisions [12]. These results highlight the need to increase the knowledge of social patterns of health literacy in older populations to better understand the corresponding inequalities in health literacy and its potential consequences. Yet, there has not been a comprehensive and representative health literacy survey on Switzerland's older adults' population. The study we present begins to close this gap, and aims to (a) measure the level of health literacy in older adults living in Switzerland and (b) identify its association with the individuals' social, regional, and health characteristics.

Methods

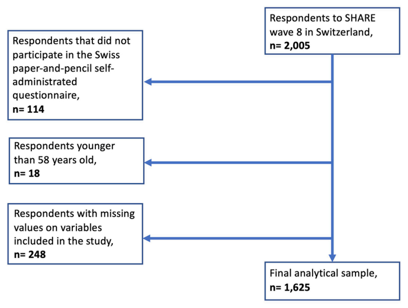
We use data from the Survey of Health, Ageing and Retirement in Europe (SHARE), a biennial population-based longitudinal study of Europeans aged 50 years and older that started in 2004 [13]. SHARE collects information on health, socioeconomic status, and social networks of targeted respondents and their partners in 27 European countries and Israel, using Computer-Assisted Personal Interviewing (CAPI). In Switzerland, a random sample of older individuals were invited to participate in the longitudinal SHARE sample and have been invited to participate in the survey every two years. During each survey round, respondents give their consent to participate in the SHARE study twice: when they accept the invitation to schedule a personal interview and when they take part in the face-to-face interview. In addition to an internationally harmonised in-person interview, respondents answer a country-specific paper-and-pencil self-administered questionnaire. Our database thus combined the Swiss questionnaire containing a short health literacy assessment with the variables from the main interview. These data were collected for the 8th wave of SHARE, between October 2019 and the beginning of March 2020. SHARE wave 8 included 2,005 participants in Switzerland, either as targeted respondents or their partners. Among them, 1,891 individuals also completed the self-administrated questionnaire, resulting in a cooperation rate of 94.3%. The Swiss SHARE sample was designed to be nationally representative of individuals aged 50 years and older and their partners. It is periodically refreshed to maintain its representativeness of the target population. Since the last refreshment sample for SHARE Switzerland took place in 2011, the Swiss SHARE sample of wave 8 (2019/2020) is no longer representative of the population of adults aged 50 to 58. Therefore, our study only includes respondents aged 58 and older to be representative of Swiss citizens. Finally, after eliminating 18 respondents younger than 58 years old and 248 respondents with missing responses on some variables included in this study, our analytical sample comprises 1,625 participants (Figure 1).

Measures

Outcome variables

HLS-EU-Q16. The Swiss drop-off questionnaire included the 16 items of the short version of the European Health Literacy Survey questionnaire developed by the HLS-EU consortium [5]. The scale consists of 16 items (see Appendix) measuring health literacy within three domains: health care, disease prevention, health promotion, and four stages of information processing, which includes accessing health information, understanding health information, processing health information, applying health information. Each item consists of concrete health-relevant tasks or situations that respondents rate on a 4-point Likert scale with answers ranging from "very easy," "fairly easy," "fairly difficult," to "very difficult." Following an approach suggested by Pelikan, Ganahl, Van den Broucke and Sorensen on how to measure health literacy in the general populations [3], each answer is dichotomised with a value of "0" for "fairly difficult" and "very difficult" and a value of "1" for the categories "very easy" and "fairly easy" [3]. Missing values

Figure 1: Flow chart.



were treated as 0, and the final health literacy score only includes respondents with no more than two missing values on the items. In total, 123 respondents (7.6%) had one or two missing values on the 16 items. The final health literacy score ranges from 0 to 16 and can be divided into three categories: inadequate (0–8), problematic (9–12), and sufficient (13–16) or in a binary variable combining the two upper categories [i.e., 0: not inadequate (9–16), 1: inadequate (0–8)]. In addition to the health literacy scores, seven sub-indices were constructed based on the different items pertaining to the three health domains and four literacy information processing stages. To make our analysis more comparable to previous studies, the health literacy score and the seven sub-indices were standardised on a scale from a minimum of 0 to a maximum of 50 following the formula: Index = (mean – 1) x 50/3 [7]. The standardisation consists of putting the indices constructed with a different number of items on the same scale; this process allows comparing the scores between all the indices.

Independent variables

To assess social differences in health literacy, our statistical models include information on gender (0 = male, 1 = female), age group (58–64 years, 65–74 years, 75+ years), and education level, which was grouped into three categories based on the International Standard Classification of Education (ISCED) of 2017 [14] (low = ISCED levels 0-1–2, secondary = ISCED levels 3–4, tertiary = ISCED levels 5–6). Our measure of partnership status considered all types of partnership rather than just focusing on legal marriage (0 = has a partner, 1 = has no partner). Respondents' perceived financial situation was measured based on the question: "Is your household able to make ends meet?" with permissible answers being recoded into three groups (1 = easily, 2 = fairly easily, 3 = with difficulty), merging the two highest categories "with some difficulty" and "with great difficulty" into the category "with difficulty." We also used information on the major linguistic regions of Switzerland based on the language of the questionnaire (German, French, or Italian) and on the living environment, namely whether respondents lived in an urban or rural area (0 = urban, 1 = rural). Finally, we assessed respondents' self-rated health status; for brevity, the original five-point Likert scale to measure self-rated health (5 = excellent, 4 = very good, 3 = good, 2 = fair, 1 = poor) was recoded by combining the two outer categories to obtain a three-point scale (1 = poor/fair health, 2 = good health, 3 = very good/excellent health).

Statistical analysis

We used unweighted number counts and weighted proportion estimation to assess the relative frequencies of all variables used in our final analytical sample of adults aged 58 and older residing in Switzerland. Specifically, to obtain descriptive statistics representative of the population of interest, we calibrated the sample using cross-sectional weights provided in the SHARE data. Survey weights can help to address challenges related to nonresponse and sample attrition. SHARE calibration of the weight relies on the approach Deville and Särndal (1992), which aligns the sample and population distributions [15]. The internal consistency and reliability for the HLS-EU-Q16 measure were assessed using Cronbach's alpha. Moreover, the distribution of the health literacy score per category of each covariate also used weighted proportion. In addition, we conducted a bivariate analysis with Pearson's chi-squared test (X2) between the health literacy score and each covariate. Partial associations between health literacy outcomes and respondents' characteristics were estimated using unweighted ordinary least squares regression (HL score), probit regression (HL binary), and multivariable ordered probit model (HL grouped), whose results are reported in terms of average marginal effects. Testing these associations on three statistical models permits a robustness check of the estimates. Finally, adjusted associations of the overall standardised health literacy score and its seven sub-indices with respondent's sociodemographic characteristics were assessed using unweighted multivariable ordinary least squares regression. The estimated standard errors were adjusted to account for the possibility of dependencies in the observations as both partners of the same couple may participate in our study, which increases the chances of similar responses. The regressions were hence clustered at the household level using the command option “cluster” of STATA to account for such potential dependencies. All estimations were performed using STATA/SE 17.0 software (STATA Corporation, College Station, TX).

Ethical approval

Our study obtained ethical approval number 66/14 from the ethics committee of the canton of Vaud, Switzerland, in March 2014.

Results

Regarding the measurement instrument of health literacy, the HLS-EU-Q16, Cronbach's alpha indicated a high internal consistency and reliability as the coefficients were above 0.9. Table 1 presents the key characteristics of our weighted analytical sample. The proportion of women in our sample was 50%, the mean age was 73.4 years old (SD: 8.5), and the majority of respondents ranged between the age of 58 and 64 years (45%). Almost three-quarters of respondents had a partner (72%), and 63% had a secondary educational degree. Most of the respondents reported that it was "easy" (57%) or "fairly easy" (30%) to make ends meet at the end of the month. Regarding regional characteristics, (70%) of the respondents lived in the German-speaking part of Switzerland, and 59% lived in a rural area. Most respondents reported being healthy, with only 16% indicating having "poor" or "fair" health.

Figure 2 displays the weighted proportion of answers for each health literacy item grouped by their respective health domain. Overall, less than 35% of respondents systematically reported finding it "very difficult" or "fairly difficult" to deal with one of the seven items from the health care domain. Only 2.3% reported having difficulties understanding doctors’ or pharmacists’ instructions on how to take a prescribed medication, 3.4% reported difficulties in following instructions from doctors or pharmacists, 6.6% in understanding what doctors say, 8.4% in finding out where to get professional help in case of illness, 9.6% in finding information on treatments of illnesses that concern the person, 13.9% in using information the doctor gives to make decisions, and 34.3% in judging when there is a need to get a second opinion from another doctor.

Less than 46% of responded reported difficulties with any of the five related HLS-EU-Q16 items concerning disease prevention. The proportion of respondents stating that it was "very difficult" or "fairly difficult" to understand health warnings about behaviour such as smoking, low physical activity, and drinking too much was 2.7%, while 6.2% reported difficulties in understanding the need for health screening, 24.5% in finding information on how to manage mental health problems like stress or depression, 37.9% in deciding how to protect oneself from illness based on information in the media, and 45.6% to judge if the information on health risks in the media is reliable.

Finally, less than 25% found it "very difficult" or "fairly difficult" to deal with different types of issues/aspects related to health promotion. A minority of 10.4% of respondents had difficulties judging which everyday behaviours are related to the person's health, 12.1% understanding health advice from family or friends, 12.4% learning about activities that benefit mental well-being, and 24.4% understanding information in the media on healthy living.

Table 2 shows the overall distribution of the three-category health literacy score and its bivariate distribution by key respondent characteristics. Overall, 6.8% of the respondents had inadequate health literacy, 24.6% problematic health literacy, and 68.6% sufficient health literacy. The bivariate analysis between health literacy and respondents' characteristics showed statistically significant correlations for gender (p <0.008), age (p <0.004), education (p <0.001), financial situation (p <0.001), and self-rated health (p <0.001). Women had higher levels of health literacy than men. Being older was correlated with lower health literacy levels, while higher education, better financial situation, and higher self-rated health were positively correlated with health literacy. Respondents' partnerships status, language, and the living area were not shown to be correlated with health literacy.

Table 3 presents adjusted partial associations between health literacy and respondent characteristics based on multivariable regression, probit, and ordered probit models depending on the outcome under consideration. Overall, women were more likely to have higher health literacy scores (p <0.001) and were less likely to have inadequate and problematic levels of health literacy than men (p <0.001). Respondents with a secondary (p <0.05) or tertiary (p <0.001) level of education were more likely to have higher health literacy scores and less likely to have inadequate and problematic levels of health literacy than respondents with a low level of education. Respondents who stated that they were able to make ends meet easily were more likely to have higher health literacy scores (p <0.01) and less likely to have inadequate and problematic health literacy levels than those reporting difficulties in making ends meet (p <0.05). Finally, respondents with good/very good or excellent self-rated health (p <0.001) were more likely to have a higher health literacy score and less likely to have inadequate and problematic levels of health literacy than those who reported being in poor or fair health. There was no statistically significant partial association between health literacy and respondent's age, partnership status, and language once other characteristics were accounted for in our models.

Table 4 shows multivariable regressions of the overall standardised health literacy score and the seven standardised sub-indices on the covariates. The adjusted partial associations of health literacy with gender, education, financial situation, and self-rated health are generally similar to those documented above. There were also statistically significant results among linguistic regions on a few sub-indices.

Table 1:
Characteristics of the study population, adults aged 58+, SHARE Switzerland, 2019/2020, n = 1,625.

		Unweighted	**Weighted**	
		n	%	CI
Gender	Male	762	50.4	[46.2–54.6]
	Female	863	49.6	[45.4–53.8]
Age groups	58–64 years	263	45.3	[40.0–50.7]
	65–74 years	678	27.5	[24.5–30.8]
	75+ years	684	27.2	[24.2–30.4]
Education	Low	289	16.0	[13.1–19.4]
	Secondary	1,015	63.1	[58.5–67.4]
	Tertiary	321	20.9	[17.2–25.2]
Partnership status	Has a partner	1,218	72.1	[67.7–76.1]
	No partner	407	27.9	[23.9–32.3]
Make ends meet	Easily	896	56.9	[52.2–61.5]
	Fairly easily	517	30.5	[26.5–34.9]
	With difficulty	212	12.6	[9.9–15.9]
Language	German	1,152	70.5	[65.7–74.9]
	French	414	26.6	[22.3–31.4]
	Italian	59	2.9	[1.9–4.2]
Living area	Urban	743	41.3	[36.7–46.0]
	Rural	882	58.7	[54.0–63.3]
Self–rated health	Poor/fair health	308	16.5	[13.5–19.9]
	Good health	685	37.6	[33.3–42.2]
	Very good/excellent health	632	45.9	[40.9–50.9]

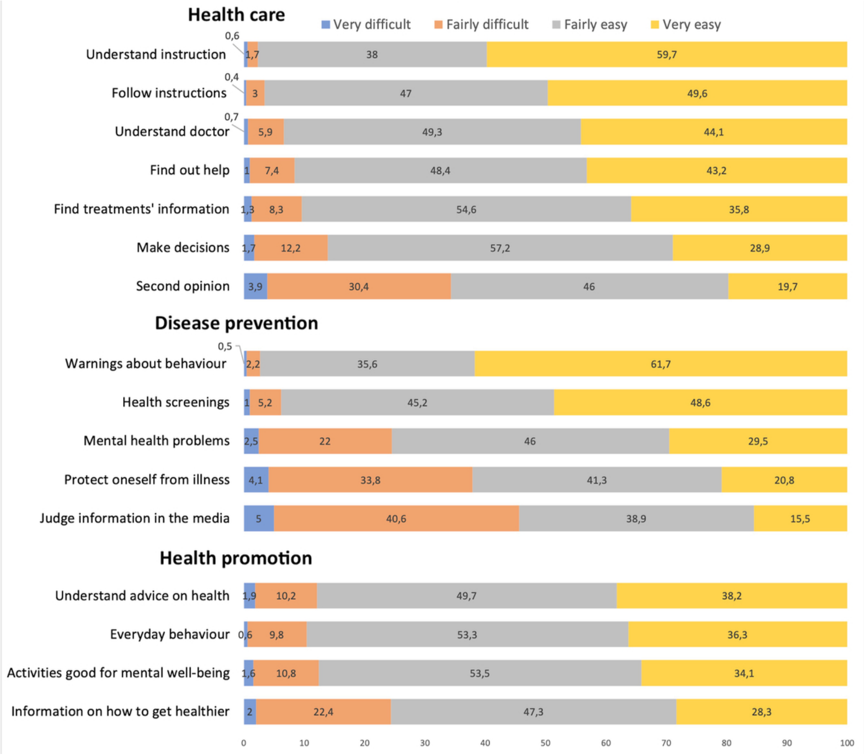
Note: unweighted and weighted number of observations for the whole sample. n = number; CI = confidence interval.

Discussion

To the best of our knowledge, our study is the first nationally representative population-based study of health literacy of adults aged 58 and older in Switzerland. The HLS-EU-Q16 allows us to draw a comprehensive picture of health literacy based on individuals' self-assessed competencies to seek, understand, process and use health information to make decisions in everyday life. In addition, as the HLS-EU-Q16 is an instrument that is used internationally, it allows for comparisons between countries. The analysis showed that about one-third of older adults in Switzerland had inadequate or problematic levels of health literacy. Specifically, 6.8% had an inadequate level of health literacy, and 24.6% had a problematic level of health literacy. Multivariable analyses indicated that — holding other characteristics fixed — health literacy was lower in men, individuals with low levels of education and people who reported difficult in making their ends meet, and those with bad self-rated health. Most older adults in Switzerland found it easy to navigate the health care system and use appropriate health information. The health-related aspects where respondents perceived more difficulties were managing mental health problems, asking for a second opinion from another doctor, protecting oneself from illness based on information in the media, judging if the information on health risks in the media is reliable, and understanding information in the media on how to get healthier.

In comparison to previous nationwide studies of health literacy in Switzerland in 2020 [11], our study indicates a relatively higher level of health literacy. However, the age range differs considerably from our study population as the one from the FOPH, which included individuals 15 years old and above. Older adults tend to have more experience and are more likely to be confronted with health issues which may help them be more familiar with the healthcare system. Moreover, the study from the FOPH included more respondents with a migration background and difficulties with the local language than there are in our research. Additionally, the method of data collection was not the same; our study uses face-to-face interviews (CAPI) while the one from the FOPH uses a mix of online interviews (CAWI) and telephone interviews (CAPI). We feel the best option for interviewing older adults is in person as it avoids potential challenges with using a laptop and lessens the chance of hearing problems, which could occur over the phone. Some variations may also come from the fact that the study from the FOPH had 47 items while our study only included 16 items; in comparison, the shorter scale presents easier questions on health issues that are more common, which may allow individuals to have a

Figure 2: Short version of the European Health Literacy Survey questionnaire (HLS-EU-Q16), percentage of respondents per categories, adults aged 58+, SHARE Switzerland, 2019/2020, n = 1,625.



better score [16, 17]. Compared to other European countries, our results are close to those with high health literacy distribution, such as Austria [18]. A potential explanation for the high levels of health literacy present in our results could be that older adults in Switzerland are often well-educated individuals with relatively good health and few financial difficulties.

The general health literacy score varied significantly between respondents depending on their sociodemographic characteristics such as gender, education, financial situation, and self-rated health status. We found that women had better health literacy scores than men. This result was statistically significant with the general measures of health literacy and through the different sub-indices. Other studies on general populations also found that women perceived fewer difficulties regarding health-related aspects than men [17, 19]. Gender differences in attitudes toward health and use of healthcare services are well documented: women have, on average, better overall adherence to health screening and prevention programs, and they make greater use of medical consultation [20]. The gender gap in health could be explained by women's traditional role as caregivers, which remains relevant today and contributes to women's increased knowledge and skills in attention to health [21].

Our analyses showed a strong positive association between education and health literacy scores and sub-indices. This result is not surprising as education develops transversal skills measured in the health literacy scale and applied to health-related issues [4]. Previous research demonstrated that communicating health information is not enough to improve health literacy, and educating individuals is fundamental [22–24]. For older adults, the conservation and development of an adequate level of health literacy depend mainly on whether or not they practice lifelong learning activities such as formal education, reading practices, internet use, and social or volunteering actions [2, 25].

Better health literacy is also associated with better phyical health; in our analyses, respondents with better self-rated health, a good predictor of individuals' health status [26], were more likely to have a higher health literacy score. Although we don't know exactly in which direction this association goes, it is likely that health literacy indirectly impacts health through multiple mechanisms; for instance, increased health literacy can lead to better behaviour such as more exercise or lower smoking rate or drinking, which will ultimately improve health status [5]. Moreover, there is a positive association between education level, health literacy, and self-rated health. A Dutch study showed that health literacy mediates the associations between education and self-reported health and concludes that improving health literacy could be a useful strategy to reduce health inequalities related to education [27].

Another important factor associated with low health literacy in our study is financial strain. Compared to individuals for whom it was easy to make ends meet, respondents with financial difficulty had lower health literacy. The HLS-EU consortium that developed the European Health Literacy Survey questionnaire found similar results concerning the negative association between health literacy and financial deprivation [7]. Similarly, in the 2020 nationwide study on health literacy in Switzerland by the FOPH, financial deprivation was one of the strongest drivers of low health literacy levels [28]. In another study, the authors describe the associations between individuals' sociodemographic characteristics such as education level or financial limitation, health-related behaviour, and health literacy, and attest that globally individuals with higher socioeconomic status tend

Table 2:
Distribution of the three-category health literacy on the covariates, adults aged 58+, SHARE Switzerland, 2019/2020,n = 1,625

		Health literacy scores (grouped)			**p-value**
		Inadequate	**Problematic**	**Sufficient**	
		% [95% CI]	**% [95% CI]**	**% [95% CI]**	
Total		6.8 [5.0–9.1]	24.6 [20.6–29.1]	68.6 [64.0–72.9]	
Gender	Male	7.8 [5.1–11.9]	24.3 [18.3–31.6]	67.8 [60.4–74.4]	
	Female	5.7 [3.9–8.3]	24.9 [20.4–30.1]	69.4 [64.2–74.2]	<0.008
Age groups	55–64 years	5.4 [2.5–11.2]	25.0 [17.1–35.1]	69.6 [59.5–78.1]	
	65–74 years	5.8 [4.2–8.0]	22.7 [19.5–26.2]	71.5 [67.8–75.0]	
	75+ years	10.1 [8.0–12.8]	25.9 [22.7–29.5]	64.0 [60.1–67.7]	<0.004
Education	Low	14.3 [9.1–21.7]	26.4 [18.8–35.8]	59.3 [49.1–68.8]	
	Secondary	6.6 [4.4–9.9]	27.4 [22.2–33.4]	65.9 [60.0–71.4]	
	Tertiary	1.5 [0.7–3.1]	14.7 [9.9–21.3]	83.8 [77.0–88.8]	<0.001
Partnership status	Has a partner	5.9 [4.4–8.0]	24.5 [19.6–30.0]	69.6 [64.1–7.47]	
	No partner	9.0 [4.8–16.3]	25.0 [18.5–33.0]	66.0 [57.4–73.6]	<0.595
Make ends meet	Easily	5.3 [3.1–9.0]	20.0 [15.5–25.5]	74.6 [68.8–79.7]	
	Fairly easily	6.8 [4.2–10.7]	29.5 [22.5–37.6]	63.7 [55.7–71.0]	
	With difficulty	13.2 [8.4–20.2]	33.6 [22.1–47.4]	53.3 [40.6–65.5]	<0.001
Language	German	6.3 [4.2–9.2]	21.3 [17.3–26.1]	72.4 [67.3–76.9]	
	French	7.1 [4.2–11.7]	32.6 [23.3–43.5]	60.3 [50.1–69.7]	
	Italian	16.1 [5.2–40.3]	30.7 [16.0–50.7]	53.2 [36.0–69.7]	<0.272
Living area	No	6.7 [4.8–9.1]	23.6 [18.6–29.4]	69.8 [63.8–75.1]	
	Yes	6.9 [4.3–10.7]	25.4 [19.7–32.2]	67.8 [61.0–73.9]	<0.273
Self–rated health	Poor/fair health	15.2 [9.9–22.8]	35.6 [25.6–47.0]	49.2 [39.3–59.2]	
	Good health	6.9 [5.2–9.1]	25.1 [19.8–31.3]	68.0 [61.7–73.7]	
	Very good/excellent health	3.6 [1.4–9.1]	20.3 [14.6–27.4]	76.1 [68.6–82.3]	<0.001

Note: all proportions are weighted, CI = confidence interval. HLS-EU-Q16 Score: 0–8 = inadequate, 9–12 = problematic, 13–16 = sufficient.

to have better self-management regarding health issues [29]. Our findings outline a social gradient in health literacy in older adults living in Switzerland that may produce health inequality. Individuals with lower education, more limited financial resources and poor health status are at risk of being disadvantaged in accessing and using health services. Public health policies should use health literacy measures such as the European Health Literacy Survey questionnaire to target individuals affected by this triple burden. Health literacy interventions could include the use of simplified health information and accessible and easy-to-use eHealth tools [30]. However, although digitalization radically changes how individuals find information on health issues, policies should be particularly careful with older adults as they tend to display more difficulties with accessing digital information and lower levels of digital health literacy [11]. Improving patient-provider communication could also increase the shared decision-making and help the individuals to manage their health better. Moreover, a policy that would ask all citizens to answer a health literacy questionnaire periodically and offer specific intervention to respondents with an inadequate level of health literacy could help alleviate remaining social health inequalities in the Swiss population.

Limitations

Our study has several limitations. First, the HLS-EU-Q16 questionnaire is a subjective measure that can include reporting bias where respondents would overrate their skills and underrate their problems. Nevertheless, the short version of the HLS-EU questionnaire also presents some advantages: it is more convenient as it is quicker for older adults to answer and is also a validated instrument [31, 32]. Second, our study findings may be challenged by remaining concerns about the representativeness of SHARE or issues related to missing data, which may bias our estimates. The selection effects and attrition might underrepresent a vulnerable group of very old adults or individuals in bad health disposition who did not participate in the main SHARE study due to their low literacy, education, unwillingness to participate, or health conditions. In addition, even if the study SHARE follows individuals in nursing homes, when necessary, such interviews remain challenging and not always feasible. In the study, missed participations were not a significant concern as the number of respondents who did not participate in the drop-off questionnaire was extremely low. Then, no critical tendency appeared when regressing on the set of covariates those who were not included due to missing values on the variables used in the analysis. Finally, the current design of the study does not allow us to determine a causal effect.

Table 3:
Partial associations of health literacy with respondents’ sociodemographic characteristics; health literacy score (0–16), two-category (0: not inadequate, 1: inadequate) and three-category (1: inadequate, 2: problematic, 3: sufficient), adults aged 58+, SHARE Switzerland, 2019/2020, n = 1,625.

		OLS regression (HL score)	**Probit regression [Inadequate** AME (SE)]	**Oprobit regression [Inadequate – Problematic** AME (SE)]	
Gender (male)	Female	0.67***	**–0.05*****	–0.03***	–0.06***
		(0.14)	(0.01)	(0.01)	(0.01)
Age group (58–64 years)	65–74 years	0.11	–0.03	–0.00	–0.00
		(0.19)	(0.02)	(0.01)	(0.02)
	75+ years	–0.13	–0.01	0.01	0.02
		(0.21)	(0.02)	(0.01)	(0.02)
Education (low)	Secondary	0.44*	–0.05*	–0.03	–0.04*
		(0.22)	(0.02)	(0.01)	(0.02)
	Tertiary	1.22***	–0.10***	–0.07***	–0.12***
		(0.24)	(0.02)	(0.02)	(0.02)
Partnership status (has a partner)	No partner	0.07	0.00	–0.00	–0.01
		(0.18)	(0.02)	(0.01)	(0.02)
Make ends meet (easily)	Fairly easily	–0.19	–0.01	0.01	0.02
		(0.17)	(0.01)	(0.01)	(0.02)
	With difficulty	–0.81**	0.05*	0.03*	0.05*
		(0.27)	(0.02)	(0.02)	(0.02)
Language [German (ch)]	French (ch)	0.04	–0.00	0.01	0.01
		(0.18)	(0.02)	(0.01)	(0.02)
	Italian (ch)	–0.48	0.04	0.03	0.04
		(0.50)	(0.05)	(0.03)	(0.04)
Living area (urban)	Rural	–0.12	0.01	0.01	0.02
		(0.15)	(0.01)	(0.01)	(0.01)
Self-rated health (poor/fair health)	Good health	0.97***	–0.03	–0.05***	–0.06***
		(0.23)	(0.02)	(0.02)	(0.02)
	Very good/excellent health	1.59***	–0.09***	–0.08***	–0.12***
		(0.23)	(0.02)	(0.02)	(0.02)
Observations		1625	1625	1625	1625

Note: this table shows an Ordinary Least Squares (OLS) regression of the Health Literacy (HL) score on the covariates, a probit regression of the two-category HL variable on the covariates, and an oprobit regression of the three-category HL score on the covariates. The table shows average marginal effects (AMEs) and standard errors in brackets with significance level $^{*}p < 0.05$, $^{**}p < 0.01$, $^{***}p < 0.001$. Concerning the interpretation of the average marginal effects, the AME for gender in the probit regression in bold above, for instance, means that women have a 5-percentage point smaller probability of inadequate health literacy compared to men.

Conclusion

Despite a good level of health in Switzerland, which has one of the longest life expectancies in the world [33], one-third of older citizens report having difficulty managing their health. Our findings showed that men, individuals with low education, financial difficulties, and poor self-assessed health status are particularly at risk of presenting inadequate health literacy levels. The combination of social and health vulnerability with a low level of health literacy makes these population groups more likely to experience health inequalities. These findings emphasise that public health policies are needed to overcome this social gradient regarding health inequalities in the population. Accordingly, the FOPH provides teaching materials for individuals with low health literacy and information for healthcare providers on how they can promote the health literacy level of their patients [34]. With regards to the older adult population, health literacy screening for patients seems beneficial to overcome poor compliance with treatment and inappropriate health care decisions [35]. In addition, the promotion of lifelong learning activities and the simplification of health information accessible on the Internet could help reduce the share of individuals with inadequate health literacy levels [25].

Data sharing statement

This paper uses data from Börsch-Supan, A. (2020). Survey of Health, Ageing and Retirement in Europe (SHARE) Wave 8. Release version: 1.0.0. SHARE-ERIC. Data set. DOI: 10.6103/SHARE.w8.100. Study data already deidentified are available to the scientific community upon submitting a data requestion application to the SHARE study.

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Table 4:
Partial associations of standardised health literacy score and sub-indices with respondents' sociodemographic characteristics, adults aged 58+, SHARE Switzerland, 2019/2020, n = 1,625

		HL score	Healthcare (hc_hl)	Disease prevention (dp_hl)	Health promotion (hp_hl)	Access (oi)	Understanding (ui)	Process (pi)	Apply (ai)
Gender (male)	Female	2.03***	1.84***	1.95***	2.46***	2.36***	1.84***	2.31***	1.69***
		(0.35)	(0.37)	(0.41)	(0.45)	(0.42)	(0.36)	(0.48)	(0.43)
Age group (58–64 years)	65–74 years	0.01	0.26	–0.01	–0.39	0.05	0.15	–0.04	–0.26
		(0.53)	(0.54)	(0.64)	(0.65)	(0.61)	(0.53)	(0.71)	(0.64)
	75+ years	–0.40	0.71	–0.91	–1.71*	–0.87	–0.38	–0.34	0.12
		(0.55)	(0.56)	(0.69)	(0.69)	(0.65)	(0.56)	(0.74)	(0.66)
Education (low)	Secondary	1.37*	1.25*	1.45*	1.48*	1.34*	1.69**	1.10	1.04
		(0.54)	(0.56)	(0.64)	(0.68)	(0.64)	(0.55)	(0.70)	(0.63)
	Tertiary	4.03***	3.79***	3.86***	4.68***	3.84***	4.77***	3.34***	3.52***
		(0.65)	(0.66)	(0.79)	(0.85)	(0.78)	(0.66)	(0.87)	(0.78)
Partnership status (has a partner)	No partner	0.67	0.41	0.81	0.94	0.22	0.99*	0.75	0.55
		(0.47)	(0.49)	(0.54)	(0.58)	(0.56)	(0.47)	(0.61)	(0.57)
Make ends meet (easily)	Fairly easily	–0.90*	–0.95*	–1.11*	–0.55	–1.24*	–0.85*	–1.01	–0.46
		(0.43)	(0.44)	(0.51)	(0.54)	(0.52)	(0.43)	(0.56)	(0.51)
	With difficulty	–2.20***	–2.73***	–1.51*	–2.12*	–3.71***	–2.24***	–1.06	–1.23
		(0.66)	(0.69)	(0.77)	(0.84)	(0.82)	(0.66)	(0.83)	(0.77)
Language [German (ch)]	French (ch)	–0.69	–1.10*	0.06	–0.91	–1.17*	–1.31**	0.86	–0.37
		(0.47)	(0.48)	(0.54)	(0.57)	(0.57)	(0.46)	(0.60)	(0.54)
	Italian (ch)	–2.02	–1.02	–2.95*	–2.59	–2.80	–3.05*	0.27	–1.21
		(1.24)	(1.24)	(1.36)	(1.54)	(1.48)	(1.38)	(1.43)	(1.23)
Living area (urban)	Rural	–0.31	–0.15	–0.33	–0.57	–0.14	–0.50	–0.01	–0.47
		(0.39)	(0.40)	(0.46)	(0.48)	(0.47)	(0.39)	(0.50)	(0.46)
Self-rated health (poor/fair health)	Good health	1.85***	1.73**	1.71**	2.24***	2.44***	1.52**	1.84**	1.74**
		(0.55)	(0.60)	(0.63)	(0.67)	(0.67)	(0.57)	(0.70)	(0.65)
	Very good/excellent health	4.00***	3.56***	3.77***	5.07***	4.51***	3.51***	4.90***	3.42***
		(0.58)	(0.63)	(0.67)	(0.71)	(0.72)	(0.59)	(0.75)	(0.70)
Constant		31.96***	33.53***	30.31***	31.27***	31.77***	35.14***	26.42***	31.39***
		(0.96)	(0.98)	(1.15)	(1.24)	(1.13)	(0.97)	(1.26)	(1.11)
Observations		1625	1625	1625	1625	1625	1625	1625	1625

Note: this table shows the regressions of the standardised health literacy score and the sub-indices on covariates. Sub-indices abbreviations: health care (hc_hl), disease prevention (dp_hl), health promotion (hp_hl), access health information (oi), understanding health information (ui), process health information (pi), apply health information (ai). Estimates and standard errors in parentheses, significance level: *p <0.05, **p <0.01, ***p <0.001.

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Coi-Statement

The authors declare that they have no competing interests.

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Appendix

The questions with the 16 items from the HLS-EU-Q16 scale

First, we would like to ask you how comfortable you feel when dealing with health-related information.

For you, how easy or difficult is it to…

Answer categories: "Very easy", "Fairly easy", "Fairly difficult", "Very difficult"

Health care

1. Understand your doctor's or pharmacist's instructions on how to take a prescribed medicine?
2. Follow instructions from your doctor or pharmacist?
3. Understand what your doctor says to you?
4. Find out where to get professional help when you are ill?
5. Find information on treatments of illnesses that concern you?
6. Use the information the doctor gives you to make decisions about your illness?
7. Judge when you may need to get a second opinion from another doctor?

Disease prevention

8. Understand health warnings about behaviour such as smoking, low physical activity, and excessive drinking?

9. Understand why you need health screenings?

10. Find information on how to manage mental health problems like stress or depression?

11. Decide how you can protect yourself from illness based on information in the media?

12. Judge if the information on health risks in the media is reliable?

Health promotion

13. Understand advice on health from family members or friends?

14. Judge which everyday behaviour is related to your health?

15. Find out about activities that benefit your mental well-being?

16. Understand information in the media on how to be healthier?

4.2 Article II

Title: Perceptions and Knowledge Regarding Medical Situations at the End of Life among Older Adults in Switzerland.

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Original Article

Perceptions and Knowledge Regarding Medical Situations at the End of Life among Older Adults in Switzerland

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Abstract

Background: Perceptions and knowledge regarding end-of-life health and health care can influence individuals' advance care planning, such as the completion and content of advance directives.
Objectives: To assess older adults' perceptions of medical end-of-life situations in Switzerland along with their accuracy and corresponding associations with sociodemographic characteristics.
Design: This is an observational study.
Setting/study subjects: A nationally representative sample of adults aged 58 years and older who participated in wave 8 (2019/2020) of the Swiss part of the Survey of Health, Ageing, and Retirement in Europe (cooperation rate: 94.3%).
Measurements: Subjective likelihood of 11 end-of-life situations on a 4-point scale: very unlikely (0–25%), rather unlikely (26%–50%), rather likely (51%–75%), and very likely (76%–100%).
Results: Older adults' perceptions of end-of-life medical situations in Switzerland were rather heterogeneous and often inaccurate. Study subjects overestimated the success of cardiopulmonary resuscitation, the utility of a fourth-line chemotherapy, of hospital admission for pneumonia for patients with advanced dementia, and for artificial nutrition and hydration in the dying phase, while underestimating the effectiveness of pain management in this situation. Less than 28% of older adults correctly assessed the likelihood of dying in a nursing home, hospital, or at home, respectively. Inaccurate views were more frequent in men ($p < 0.01$) and individuals with financial difficulties ($p < 0.05$), whereas adults aged 75+ years ($p < 0.01$) and respondents from the German-speaking part of Switzerland ($p < 0.01$) had more accurate perceptions.
Conclusions: The wide variation and low accuracy of end-of-life perceptions suggest considerable scope for communication interventions about the reality of end-of-life health and health care in Switzerland.

Keywords: end of life; knowledge; older adults; perceptions; population-based study; Switzerland

Introduction

Population aging and an increasing medicalization of older age, especially at the end of life, have led to major changes in the social and health care contexts in which death occurs.[1] These trends have led to a higher predictability of the end of life and a greater importance of considering individual preferences for end-of-life care.[2] These circumstances have stimulated the development and implementation of advance care planning as a tool to better align end-of-life

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care with individuals' wishes for their end of life, which often concern diverse aspects of quality of life beyond health care.[3,4] Thus, individuals can decide about their end-of-life medical treatments, whereas direct contact with death has generally been evicted from our societies. As a result, individuals are asked to make choices about situations they have little knowledge about.

The decision to engage in advance care planning and the content of advance care plans are likely to depend on people's perceptions and knowledge regarding the reality of end-of-life health care in the setting in which they live.[5] Key aspects to consider when planning for the end of life include the risk to suffer from dementia in old age, legal liability for medical decision making at the end of life, the potential utility of different types of medical interventions at the end of life, and considerations of place of death. In Switzerland, dementia is the third leading cause of death[6]; patients with dementia tend to be a burden for their families that have to make medical decisions on their behalf[7]; detecting such illness at an early stage may allow individuals to state their preferences for medical treatments.[8,9]

Perceptions and knowledge play a crucial part in decision making regarding medical treatment; common sources of distress reported by patients are pain management,[10] even though it is well treatable by specialists,[11] artificial nutrition, and hydration treatments viewed as either compassionate or invasive,[12] cardiopulmonary resuscitation in a cardiac arrest that is usually considered as a successful medical intervention,[13] and the use of medically inappropriate treatments.[14] Finally, individuals receive different types of care, and their end-of-life experience varies depending on whether they die in a nursing home, a hospital, or at home.[15,16]

The complexity of end-of-life situations and the potentially negative consequences of an uninformed or misinformed decision on the quality of dying and death emphasize the need for early communication on end-of-life medical issues to avoid misunderstanding or misrepresentation. Communication is a central part of end-of-life care; patients and family caregivers need information about the illness and its progression.[17] Having an enlightened view of the reality of end-of-life care is, therefore, a key input into advance care planning, and reducing misconceptions and knowledge gaps about likely end-of-life outcomes may enable older adults to prepare and manage their end of life more effectively.[18]

Despite the general importance of perceptions of end-of-life realities for potential advance care planning, little is known about the perceptions of common end-of-life situations and their accuracy among older adults in the general population. To fill this knowledge gap, we used nationally representative data on adults aged 58 years and older in Switzerland to assess their perceptions of important aspects of end-of-life health and health care along with their accuracy in the Swiss context. We specifically explored individuals' perceptions and potential misrepresentations about frequent health and medical end-of-life situations concerning cognitive impairment, life-sustaining measures, medically inappropriate treatments, and place of death.

Methods

Study design and sample

We used data from the Survey of Health, Ageing and Retirement in Europe (SHARE), a European biennial population-based cohort study of adults aged 50 years and older and their partners, which collects information on health, socioeconomic status, and social networks.[19,20] The data set combines internationally harmonized face-to-face interviews and national self-administered paper-and-pencil questionnaires handed out to participants at the end of the interview. Our analytical data set includes questions from the Swiss paper-and-pencil questionnaire on end-of-life issues and sociodemographic variables merged from the face-to-face interview, both from wave 8 of the SHARE study fielded between October 2019 and the beginning of March 2020. The IRB approval: CER-VD: 66/14 (2014).

The last refreshment sample of SHARE Switzerland took place in 2011; thus, the study only includes target respondents aged 58 years and older to be nationally representative. The main interview from wave 8 of SHARE included 2005 Swiss respondents; among them, 94.3% also completed the paper-and-pencil questionnaire ($n = 1891$). After restricting the sample to participants from the age of 58 years onward and deleting all observations with missing information on at least one item used in the analysis, the total number of individuals included was 1217 (Appendix Figure A1).

Measures

Outcome variables. *Perceived frequency of different end-of-life situations.* The questionnaire included 11 frequent end-of-life health and health care situations regarding cognitive impairment, medical treatment, and place of death (Appendix Table A1). Respondents had to evaluate the frequency of occurrence of the 11 situations on a 4-point scale: 1 = very unlikely (0–25%), 2 = rather unlikely (26%–50%), 3 = rather likely (51%–75%), and 4 = very likely (76%–100%). The accuracy of perceptions of different end-of-life situations is defined by dichotomized variables where 1 indicates a correct answer and 0 an incorrect answer.

Independent variables

Sociodemographic covariates. To assess sociodemographic differences in perceived likelihood of different end-of-life situations and their accuracy, our statistical models include information on gender (0 = male, 1 = female), age group (58–64 , 65–74, and 75+ years), and education level, which was grouped into three categories based on the International Standard Classification of Education (ISCED) of 2017[21] (low = ISCED levels 0–1–2, secondary = ISCED levels 3–4, tertiary = ISCED levels 5–6). We also used information on the three main linguistic regions of Switzerland based on the language completion of the questionnaire (German, French, or Italian).

Our measure of partnership status considered all types of partnership rather than just focusing on formal marriage (0 = has a partner, 1 = has no partner). Respondents' perceived financial situation was measured based on the question: "Is your household able to make ends meet?" with permissible answers being recoded into three groups (1 = easily, 2 = fairly easily, and 3 = with difficulty). We also used information on whether individuals lived in an urban or rural area (0 = urban, 1 = rural) and respondents' self-rated health coded on a 3-point scale (1 = poor/fair health, 2 = good health, and 3 = very good/excellent health).

Statistical analysis

We calculated respondents' weighted proportion estimation per category of probabilities of the 11 end-of-life health and health care situations and indicated the correct answer based on recent studies from the literature (Appendix Table A2). The sample was calibrated using cross-sectional weights provided in the SHARE data.[22] We then determined the partial associations between the 11 end-of-life health and health care situations and the individuals' characteristics using unweighted interval regressions. Finally, we presented 11 unweighted probit regressions of variables assessing the degree of accuracy of respondents' perceptions on each situation (0 = incorrect answer, 1 = correct answer) on individuals' sociodemographic characteristics.

In addition, we also calculated a score regarding the accuracy of respondents' perceptions; the score adds 1 point for a right answer and 0; otherwise, the maximum possible value of the score is 11, and the minimum is 0. We did an ordinary least squares (OLS) regression of the score on respondents' characteristics. Moreover, since this was an exploratory study, we did not adjust for multiple comparisons. All estimations were performed using STATA/SE 17.0 software (STATA Corporation, College Station, TX, USA), with standard errors clustered at the household level.

Results

Table 1 presents the key characteristics of our sample. The proportion of women was 48%, the median age was 65 years old, with 22% of the respondents older than 75 years. Most respondents had a partner (74%). Concerning the linguistic regions, 72% were from the German-speaking part, 25% from the French-speaking region, and 3% from the Italian-speaking part. The majority had a secondary level of education (66%) and 12% a lower level. Most of the respondents reported that it was ''easy'' (58%) or ''fairly easy'' (31%) to make ends meet at the end of the month. Moreover, a majority of 59% lived in a rural area. Finally, most of the respondents self-reported to have ''good'' or ''excellent health'' (86%).

Figure 1 shows respondents' perceived likelihood of the 11 end-of-life health and health care situations with the correct answer marked by a rectangle. Regarding the likelihood of suffering from dementia at higher ages, respondents correctly perceived this likelihood to be larger at age 95 years compared with age 75 years but generally overestimated the prevalence of dementia at both ages. Although the majority of respondents reported it to be ''rather likely'' or ''very likely'' to be asked to make medical decisions on behalf of their spouse or partner in case of their decisional incapacity and the absence of an advance directive, only less than one-third of respondents selected the correct category.

Individuals overestimated the success of cardiopulmonary resuscitation, the utility of a fourth-line oncological chemotherapy, the benefit of hospital admission for pneumonia in advanced dementia, and the effect of artificial nutrition and hydration in the dying phase but underestimated the effectiveness of pain management in this context. Concerning the likelihood of different places of death, older adults in general correctly think that deaths in Switzerland mostly occur in nursing homes and hospitals, with fewer people dying at home. However, most respondents generally overestimated the likelihood of the different places of death, with <28% choosing the correct probability for dying in a nursing home, hospital, or at home, respectively.

Table 1. Characteristics of the Study Population, Adults Aged 58+ Years, Survey of Health, Ageing and Retirement in Europe Switzerland, 2019/2020 (N = 1217)

	Unweighted	*Weighted*	
	Obs	*%*	*CI*
Gender			
Male	592	52	47.7–57.2
Female	625	48	42.8–52.5
Age groups			
58–64 Years	225	49	43.5–55.2
65–74 Years	564	29	25.6–33.2
75+ Years	428	22	18.6–24.6
Partnership status			
Has a partner	955	74	69.2–79.1
No partner	262	26	20.9–30.8
Linguistic regions			
German	881	72	66.6–77.1
French	301	25	20.5–30.9
Italian	35	3	1.5–4.1
Education			
Basic	172	12	9.1–15.1
Secondary	785	66	60.3–70.6
Tertiary	260	22	18.1–27.8
Make ends meet			
Easily	685	58	52.1–62.8
Fairly easily	387	31	26.2–36.1
With difficulty	145	11	8.6–15.4
Living area			
Urban	549	41	35.3–46.1
Rural	668	59	53.9–64.7
Self-rated health			
Poor/fair health	205	14	11.3–18.3
Good health	499	38	32.5–42.9
Excellent health	513	48	42.3–53.7

Unweighted and weighted number of observations for the whole sample.

Table 2 gives the partial associations between each respondents' perceptions of end-of-life health and health care situations and the individuals' characteristics. Overall, the results showed significant associations of perceptions with respondents' gender, age, education level, linguistic region, and self-rated health.

Table 3 presents the partial associations between the degree of accuracy of respondents' perceptions on the 11 end-of-life health and health care situations and individuals' sociodemographic characteristics. The results from the score regarding the accuracy showed that, overall, compared with men, women were more likely to pick the correct answer category ($p < 0.01$). Then, compared with the younger group, respondents older than 75 years were more likely to give accurate answers ($p < 0.01$). In addition, compared with the French-speaking part of Switzerland, respondents from the German-speaking region were more likely to answer correctly ($p < 0.01$). Finally, respondents reporting that it is

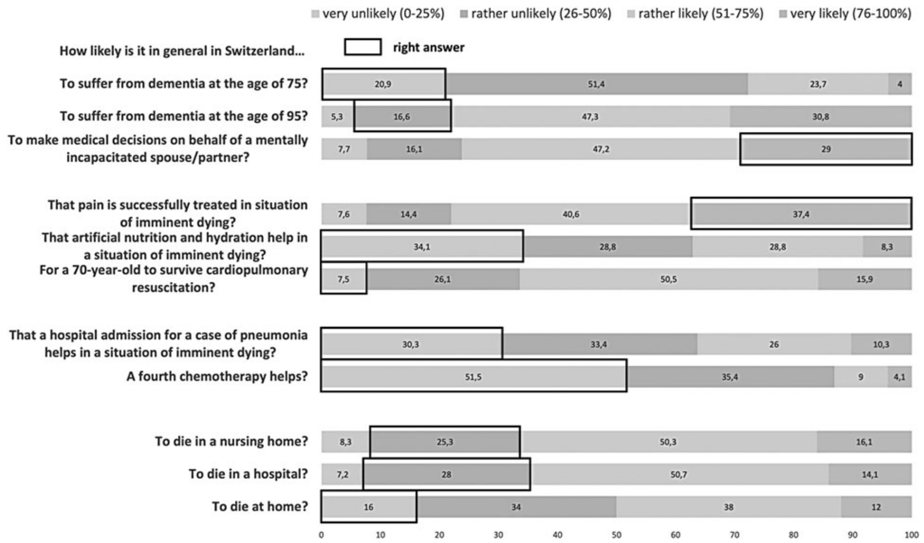

FIG. 1. Percentage of respondents per categories of each end-of-life representations, adults aged 58+ years, SHARE Switzerland, 2019/2020, $n = 1217$. SHARE, Survey of Health, Ageing and Retirement in Europe.

difficult to make ends meet compared with those with financial facilities were less likely to choose the right answer ($p < 0.05$).

Discussion

To the best of our knowledge, our study is the first nationally representative population-based study to assess older adults' perceptions and accuracy of health and health care at end-of-life situations in Switzerland. We found considerable heterogeneity in older adults' end-of-life representations with overestimation of the prevalence of dementia, rather low level of accuracy regarding pain management effectiveness and artificial nutrition and hydration utility in a situation of imminent death, unrealistic expectations of the survival rate after cardiopulmonary resuscitation at older ages, and high percentages of inaccuracy regarding the place of death in Switzerland. In addition, our findings show differences in perceptions of end-of-life health and health care situations and their accuracy among some population groups in Switzerland.

Cognitive impairment

In Switzerland, the prevalence estimate of dementia is <5% for individuals aged <75 years old and ∼45% for adults of 95 years old.[23] Most respondents overestimated the likelihood to suffer from dementia at the age of 75 and 95 years. This result may reflect a relative ignorance of dementia in the general population.

The frequent misrepresentations of dementia result in stigmatization and add barriers to early detection and treatment,[24] which may disadvantage individuals affected by dementia regarding their autonomy at the end of life, and shift the weight of treatment decisions to their partner or family. Indeed, in Switzerland, the federal law stipulates that if a person does not have decision-making capacity and has not designated a proxy in the advance directive, the person who has to decide is the partner of the patient.[25]

Medical treatment

Irrespective of the effectiveness of medical treatment, a common fear is that dying patients would suffer from severe pain, negatively affecting the quality of their end of life.[26] In our study, respondents of the older aged group were the most skeptical regarding successful treatment of pain in a situation of imminent dying, whereas individuals with a higher level of education and better self-rated health were the most optimistic regarding chances of effective pain management.

It has been reported that patients and family members often request health care specialists to administer oral nutrition and fluids continuously.[27,28] Yet, artificial nutrition and hydration during the dying phase seem not to benefit patients.[29] In our sample, however, many respondents believed that artificial nutrition and hydration are unlikely to help in a situation of imminent dying. This belief was stronger for women, consistent with other studies showing that women prefer to refrain from treatments that could deteriorate their quality of life.[30–32]

Differences within linguistic regions also appeared; respondents from German-speaking Switzerland, compared with the French-speaking and Italian-speaking parts, stated less often that artificial nutrition and hydration help in imminent dying. The variation within linguistic regions is potentially due to differences in cultural or religious beliefs.[33]

Finally, in our sample, most respondents believed it is likely for a 70 years old to survive cardiopulmonary resuscitation outside of a hospital. This result shows that older adults in Switzerland had exceedingly unrealistic

Table 2. Interval Regressions of the End-of-Life Representations' Items on the Covariates, Adults Aged 58+ Years, Survey of Health, Ageing and Retirement in Europe Switzerland, 2019/2020 (N = 1217)

	Dementia 75	*Dementia 95*	*Decisions*	*Pain*	*Artificial*	*Cardiopulmonary*	*Pneumonia*	*Chemotherapy*	*Nursing*	*Hospital*	*Home*
Gender (male)											
Female	**2.71***	3.62**	2.77*	1.99	−5.77***	0.21	−3.73**	0.73	4.32***	4.96***	−4.02***
	(1.15)	(1.22)	(1.27)	(1.31)	(1.40)	(1.22)	(1.43)	(1.19)	(1.17)	(1.14)	(1.22)
Age group (58–64 years)											
65–74 Years	−1.60	−1.07	−1.64	−0.67	0.36	−2.77	−3.36	−0.05	−3.12	0.35	−2.43
	(1.48)	(1.72)	(1.71)	(1.83)	(2.00)	(1.69)	(1.94)	(1.74)	(1.63)	(1.63)	(1.75)
75+ Years	−7.90***	−6.14**	−6.64***	−4.93*	−3.53	−3.81*	−5.79**	−1.80	−5.98***	−0.90	0.12
	(1.72)	(1.88)	(1.89)	(2.02)	(2.09)	(1.88)	(2.12)	(1.87)	(1.77)	(1.79)	(1.92)
Partnership status (has a partner)											
No partner	0.11	−3.70*	−3.16	0.28	−0.08	−2.02	−0.73	−2.11	1.08	−1.62	−0.15
	(1.51)	(1.62)	(1.64)	(1.68)	(1.79)	(1.67)	(1.86)	(1.56)	(1.57)	(1.53)	(1.64)
Linguistic regions (German)											
French	−0.73	1.65	1.78	−0.29	7.26***	3.22*	3.43*	−2.93*	6.90***	2.52	−5.54***
	(1.31)	(1.49)	(1.44)	(1.52)	(1.66)	(1.47)	(1.68)	(1.44)	(1.46)	(1.37)	(1.50)
Italian	3.03	9.10**	−3.72	4.75	13.41**	4.87	0.03	6.97	12.61***	6.18	−5.72
	(4.36)	(3.12)	(4.93)	(3.60)	(4.77)	(4.33)	(4.85)	(4.87)	(2.60)	(3.56)	(3.38)
Education (low)											
Secondary	−1.17	1.49	−1.07	0.85	−1.19	1.32	−1.37	−4.76*	0.57	2.88	−1.14
	(1.87)	(2.07)	(2.06)	(2.10)	(2.14)	(1.98)	(2.24)	(2.17)	(1.90)	(1.92)	(1.87)
Tertiary	−3.91	4.90*	2.70	6.47**	−2.00	2.16	−4.25	−5.68*	1.39	1.34	−1.83
	(2.07)	(2.33)	(2.32)	(2.34)	(2.54)	(2.31)	(2.67)	(2.45)	(2.15)	(2.22)	(2.19)
Make ends meet (easily)											
Fairly easily	−0.75	2.12	0.75	−1.72	1.21	0.18	−0.06	−0.22	−0.72	−0.45	1.96
	(1.32)	(1.45)	(1.45)	(1.56)	(1.57)	(1.47)	(1.64)	(1.38)	(1.34)	(1.28)	(1.44)
With difficulty	2.74	0.43	−0.82	−2.02	2.60	0.61	3.95	1.24	−1.93	−3.21	2.56
	(2.29)	(2.41)	(2.13)	(2.25)	(2.52)	(2.10)	(2.42)	(2.16)	(2.21)	(2.00)	(2.16)
Living area (urban)											
Rural	−0.22	1.11	0.48	−0.31	0.17	1.05	0.28	−1.02	−0.05	−1.07	−0.34
	(1.18)	(1.28)	(1.33)	(1.36)	(1.44)	(1.28)	(1.49)	(1.27)	(1.20)	(1.17)	(1.29)
Self-rated health (bad health)											
Good health	1.53	−0.59	0.93	4.13*	0.25	0.04	−2.30	−2.15	−0.48	−1.37	3.68*
	(1.71)	(1.97)	(1.87)	(2.02)	(2.12)	(1.97)	(2.16)	(1.92)	(1.81)	(1.80)	(1.86)
Excellent health	−0.71	−0.08	3.49	5.55**	0.90	2.35	−2.45	−4.14*	−1.95	−1.25	5.97**
	(1.78)	(1.98)	(1.97)	(2.09)	(2.17)	(2.05)	(2.24)	(1.97)	(1.92)	(1.82)	(1.94)
Observations	1217	1217	1217	1217	1217	1217	1217	1217	1217	1217	1217

This table reports the estimates for the interval regressions of the end-of-life representations' items on the covariates. Standard errors in parentheses have the following significance levels $*p < 0.05$, $**p < 0.01$, $***p < 0.001$. Concerning the interpretation, for instance, the number on top-left in bold means that compared with men, women have 2.71% more chances to say that it is likely in general to suffer from dementia at the age of 75 years old in Switzerland.

Table 3. Probit Regressions of the Correct Answer on the End-of-Life Representations' Items on Covariates, Adults Aged 58+ years, Survey of Health, Ageing and Retirement in Europe Switzerland, 2019/2020 (N= 1217)

	Score	*Dementia 75*	*Dementia 95*	*Decisions*	*Pain*	*Artificial*	*Cardiopulmonary*	*Pneumonia*	*Chemotherapy*	*Nursing*	*Hospital*	*Home*
Gender (male)												
Female	0.24**	–0.04	**–0.06****	0.05*	0.08**	0.13***	0.02	0.11***	–0.02	**–0.05***	–0.05**	0.06*
	(0.09)	(0.02)	(0.02)	(0.03)	(0.03)	(0.03)	(0.02)	(0.03)	(0.03)	(0.03)	(0.02)	(0.03)
Age group (58–64 years)												
65–74 Years	0.05	–0.00	–0.03	–0.00	–0.02	–0.01	0.01	0.08*	–0.02	–0.03	–0.03	0.10**
	(0.13)	(0.03)	(0.03)	(0.04)	(0.04)	(0.04)	(0.02)	(0.03)	(0.04)	(0.03)	(0.02)	(0.04)
75+ Years	0.41**	0.23***	0.02	–0.10*	–0.07	0.04	0.05	0.13**	0.03	0.04	–0.01	0.05
	(0.14)	(0.04)	(0.03)	(0.04)	(0.04)	(0.04)	(0.03)	(0.04)	(0.04)	(0.04)	(0.03)	(0.04)
Partnership status (has a partner)												
No partner	0.09	0.01	0.01	–0.02	0.01	0.03	0.05*	0.02	0.05	–0.06	0.05*	–0.07*
	(0.12)	(0.03)	(0.03)	(0.03)	(0.04)	(0.03)	(0.02)	(0.03)	(0.04)	(0.03)	(0.02)	(0.03)
Linguistic regions (German)												
French	–0.35**	0.03	–0.05*	–0.00	–0.05	–0.12***	–0.02	–0.06*	0.06	–0.14***	0.00	–0.01
	(0.11)	(0.03)	(0.02)	(0.03)	(0.03)	(0.03)	(0.02)	(0.03)	(0.04)	(0.03)	(0.02)	(0.03)
Italian	–0.22	0.08	–0.10*	–0.03	0.06	–0.20**	0.03	0.03	–0.09	–0.15*	–0.01	0.17
	(0.39)	(0.08)	(0.04)	(0.08)	(0.08)	(0.08)	(0.05)	(0.09)	(0.08)	(0.06)	(0.04)	(0.09)
Education (low)												
Secondary	–0.11	0.00	–0.06	–0.07	0.00	0.01	–0.00	–0.01	0.03	–0.01	–0.06*	0.04
	(0.14)	(0.04)	(0.03)	(0.04)	(0.04)	(0.04)	(0.03)	(0.04)	(0.04)	(0.04)	(0.03)	(0.04)
Tertiary	0.15	–0.00	–0.07	–0.01	0.09	0.01	–0.03	0.06	0.02	0.03	–0.05	0.10*
	(0.17)	(0.04)	(0.04)	(0.05)	(0.05)	(0.05)	(0.03)	(0.05)	(0.05)	(0.05)	(0.03)	(0.05)
Make ends meet (easily)												
Fairly easily	–0.11	0.00	–0.01	–0.00	–0.04	–0.04	–0.00	–0.01	–0.00	0.00	–0.01	–0.01
	(0.11)	(0.03)	(0.02)	(0.03)	(0.03)	(0.03)	(0.02)	(0.03)	(0.03)	(0.03)	(0.02)	(0.03)
With difficulty	–0.34*	–0.01	–0.00	–0.03	–0.07	–0.05	–0.03	–0.09*	–0.02	–0.04	0.01	–0.02
	(0.16)	(0.04)	(0.04)	(0.04)	(0.05)	(0.05)	(0.02)	(0.04)	(0.05)	(0.04)	(0.03)	(0.05)
Living area (urban)												
Rural	0.04	–0.01	–0.01	–0.00	–0.01	–0.00	–0.02	–0.00	0.01	0.03	0.02	0.03
	(0.10)	(0.02)	(0.02)	(0.03)	(0.03)	(0.03)	(0.02)	(0.03)	(0.03)	(0.03)	(0.02)	(0.03)
Self-rated health (bad health)												
Good health	–0.00	–0.03	0.01	0.01	0.02	–0.02	–0.05	0.01	0.00	–0.01	–0.01	0.08*
	(0.14)	(0.03)	(0.03)	(0.04)	(0.04)	(0.04)	(0.03)	(0.04)	(0.04)	(0.04)	(0.02)	(0.04)
Very good/ excellent health	0.16	0.00	–0.00	0.09*	0.07	–0.01	–0.05	0.04	0.06	–0.04	–0.01	0.03
	(0.14)	(0.04)	(0.03)	(0.04)	(0.04)	(0.04)	(0.03)	(0.04)	(0.04)	(0.04)	(0.02)	(0.04)
Constant	2.95***											
	(0.24)											
Observations	1217	1217	1217	1217	1217	1217	1217	1217	1217	1217	1217	1217

This table reports on the first column an OLS regression of the score regarding the accuracy of each individual's perception; the score adds 1 point for a right answer and 0; otherwise, the maximum possible value of the score is 11, and the minimum is 0. The rest of the table are probit regressions of the binary variable correct answers on the end-of-life representations' items on the covariates. Average marginal effects and standard errors in parentheses have the following significance levels *$p<0.05$, **$p<0.01$, ***$p<0.001$. The interpretation of the number in bold means that compared with men, women are 6% less likely to give the correct answer on the likelihood to suffer from dementia at the age of 95 years old in Switzerland.

expectations because the survival rate in these conditions is <8%.[34] The overoptimistic perspective adds difficulties for health care providers who have to communicate with patients and families and may lead to inappropriate medical decision making.[35]

Medically inappropriate treatments

Infectious diseases often precipitate the death of patients who are already weakened by multiple morbidities.[36] A situation emblematic of this sequence is that of patients with advanced dementia living in a nursing home who develop an acute infection such as pneumonia.[37] In that case, maintaining these patients in the nursing home and administering oral antibiotics there instead of transferring them to a hospital are more beneficial regarding quality of dying and provide considerable cost savings.[38] In our study, most respondents understood the unsuitability of a patient's hospitalization in such a situation.

Most respondents gave an accurate answer concerning the probability that a fourth-line chemotherapy would help a patient with advanced cancer after three different lines of chemotherapy failed. The chances of surviving such a medical treatment are ∼13.6% in Switzerland.[39–41] However, a portion of older adults living in Switzerland believed that medical action in these two end-of-life situations that can be considered aggressive treatments would benefit the patient. These beliefs show the need to communicate well about common end-of-life situations to ensure that everybody can make an informed assessment.

The place of death

Although most Swiss residents prefer to die at home,[42] 44% do in fact die in a nursing home, 37% in a hospital, and only 19% at home or elsewhere,[43] with an increasing trend toward dying in institutions.[44] In our study, most respondents systematically overestimated the likelihood of dying in a nursing home, a hospital, or at home. In addition, for many respondents, the addition of the three percentages was higher than 100, which showed a misunderstanding regarding the question or a lack of attention.

The percentage of misrepresentation was higher for the likelihood of dying at home; this is certainly influenced by the fact that home remains the ideal place of death for a large proportion of the population.[45] Then, respondents with poor health compared with those self-reporting good or excellent health indicated a lower probability of dying at home, maybe because older individuals and those with poor health are more likely to understand the limitations of home care services.[46] Knowing the likelihood of dying at home would allow individuals to adapt and prepare multiple aspects of their life, such as the finances, family organization, and care, to increase the chances of staying home at the end of their lives.

Limitations

Our study has some limitations. First, using a combination of qualitative and quantitative labels for the answer categories may have led to confusion among respondents. Some respondents may have just used either the qualitative or the quantitative labels when constructing their answers, which could result in measurement error and limitations in the comparability of answers with corresponding estimates from the literature. Second, respondents may have insufficiently understood the concepts of probability used in the construction of answer categories, despite having been asked similar subjective probability questions several times throughout the SHARE study.

Third, although SHARE makes every effort to remain representative of the older population in Switzerland, selective attrition from the study, notably among the oldest and most frail respondents, may result in some sample selection. Fourth, item nonresponse and corresponding sample selection effects may have biased our analysis, although our findings seem largely robust to deviations from our complete case analysis, such as the use of item-specific subsamples for each outcome.

Conclusion

The overall qualitative patterns of perceptions of many aspects of end-of-life situations of older adults in Switzerland seem largely consistent with current reality, even if their exact quantitative assessments are often rather inaccurate. Specifically, although perceptions of the success of some medical treatments seemed largely in line with available data, perceptions of the prevalence of dementia among the oldest or of the chances of success of out-of-hospital cardiopulmonary resuscitation in an older person are far from reality.

Furthermore, perceptions often vary considerably across individuals, which highlights significant knowledge gaps regarding end-of-life health and health care realities in Switzerland in parts of the population. Indeed, women, individuals of older age groups, and the better off appeared to have more accurate perceptions of end-of-life situations. Nonetheless, our study reveals significant misrepresentations of end-of-life realities among older adults in Switzerland that may lead to unrealistic expectations regarding end-of-life care, result in the disappointment of patients and families, and compromise the quality and reliability of advance care planning.

Authors' Contributions

C.M. and S.V. designed the study. C.M. conducted the analysis and drafted the article in collaboration with S.V. All authors discussed the interpretation of findings and provided critical revision of the article for important intellectual content.

Ethical Approval

Our study obtained ethical approval number 66/14 from the ethics committee of the canton of Vaud, Switzerland, in March 2014.

Data Sharing

This article uses data from Börsch-Supan, A. (2020). Survey of Health, Ageing and Retirement in Europe (SHARE) Wave 8. Release version: 1.0.0. SHARE-ERIC. Data set. DOI: 10.6103/SHARE.w8.100. Study data already deidentified are available to the scientific community upon submitting a data requestion application to the SHARE study.

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(*Appendix follows* →)

Appendix Table A1. End-of-Life Medical Situation Questions

People have representations of end-of-life medical situations. We would like to know yours.

We would like to know whether you think that the situations described hereunder and related to end of life are very unlikely (0–25%), rather unlikely (26%–50%), rather likely (51%–75%), or very likely (76%–100%).

If you do not know, please give us your best estimate.

Example: ''In your opinion, what are the chances that it is snowing tomorrow?'' If you tick ''very likely,'' you consider that the chances that it is snowing tomorrow range between 76% and 100%.

In your opinion, how likely is it in general in Switzerland…

Answer categories: ''very unlikely (0–25%),'' ''rather unlikely (26%–50%),'' ''rather likely (51%–75%),'' ''very likely (76%–100%).''

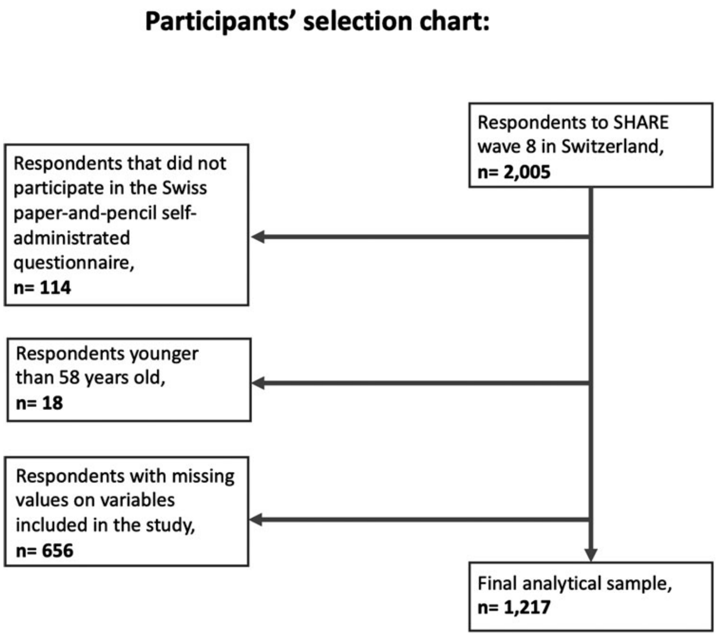
1. To suffer from dementia at the age of 75 years? **(dementia 75)**
2. To suffer from dementia at the age of 95 years? **(dementia 95)**
3. In the absence of advance directives, to be asked to make medical decisions concerning your spouse/partner should he/she become severely ill and unable to make decisions? **(decisions)**
4. That pain (of any origin) can be successfully treated in a situation of imminent dying? **(pain)**
5. That artificial nutrition and hydration helps in a situation of imminent dying? **(artificial)**
6. For a 70 years old to survive until hospital discharge from a cardiopulmonary resuscitation performed outside of a hospital after a cardiac arrest? **(cardiopulmonary)**
7. That a hospital admission in the case of pneumonia helps for a patient in a situation of imminent dying due to advanced dementia living in a nursing home? **(pneumonia)**
8. That a fourth-line chemotherapy helps a patient with advanced cancer that three different chemotherapies did not stop? **(chemotherapy)**
9. To die in a nursing home? **(nursing)**
10. To die in a hospital? **(hospital)**
11. To die at home? **(home)**

(*Appendix continues* →)

Appendix Table A2. Right Answer Categories on the 11 End-of-life Medical Situations Questions

In your opinion, how likely is it in general in Switzerland…	*Likelihood*	*References*
To suffer from dementia at the age of 75 years **(dementia 75)**?	Very unlikely (0–25%)	*In Switzerland, the prevalence estimate of dementia is lower than 5% for individuals aged less than 75 years old and approximately 45% for adults of 95 years old.*[23]
To suffer from dementia at the age of 95 **(dementia 95)**?	Rather unlikely (26%–50%)	
In the absence of advance directives, to be asked to make medical decisions concerning your spouse/partner should he/she become severely ill and unable to make decisions **(decisions)**?	Very likely (76%–100%)	*According to Swiss national law, the spouse/partner is the surrogate decision maker if the patient is unable to make decisions (Art 378 Swiss Civil Code).*
That pain (of any origin) can be successfully treated in a situation of imminent dying **(pain)**?	Very likely (76%–100%)	*In a recent population-based study on the last 30 days of life conducted in Canada, the authors found that although pain is a prevalent symptom at the end of life, less than 20% reported having severe daily pain.*[10]
That artificial nutrition and hydration help in a situation of imminent dying **(artificial)**?	Very unlikely (0–25%)	*Artificial nutrition and hydration do not positively affect the dying phase.*[27,28]
For a 70 years old to survive until hospital discharge from a cardiopulmonary resuscitation performed outside of a hospital after a cardiac arrest **(cardiopulmonary)**?	Very unlikely (0–25%)	*The survival rate for a 70 years old after a cardiopulmonary resuscitation is lower than 8%.*[34]
That a hospital admission in the case of pneumonia helps for a patient in a situation of imminent dying due to advanced dementia living in a nursing home **(pneumonia)**?	Very unlikely (0–25%)	*A study showed that treating patients directly in their nursing homes with oral antibiotics was more beneficial for their quality of dying and considerably more cost-saving than hospitalization.*[38]
That a fourth-line chemotherapy helps a patient with advanced cancer that three different chemotherapies did not stop **(chemotherapy)**?	Very unlikely (0–25%)	*Despite the increasing number of cancer survivors among the Swiss population, the likelihood that a fourth-line chemotherapy helps a patient is ∼13,6%.*[39–41]
To die in a nursing home **(nursing)**?	Rather unlikely (26%–50%)	*According to a recent study, 44% of Swiss citizens aged 65 years and older die in a nursing home, 37% in a hospital, and 19% at home or elsewhere.*[43]
To die in a hospital **(hospital)**?	Rather unlikely (26%–50%)	
To die at home **(home)**?	Very unlikely (0–25%)	

(*Appendix continues* →)



APPENDIX FIG. A1. Participants' selection chart.

4.3 Article III

Title: Overestimation of success rates of cardiopulmonary resuscitation is associated with higher preferences to be resuscitated: evidence from a national survey of older adults in Switzerland.

Authors: Clément Meier, Dr. Sarah Vilpert, Dr. Maud Wieczorek, Prof. Gian Domenico Borasio, Prof. Ralf J. Jox and Prof. Jürgen Maurer

Journal: Medical Decision Making

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Clément Meier, Sarah Vilpert, Maud Wieczorek and Jürgen Maurer designed the study. Clément Meier conducted the analysis and drafted the article. All authors discussed the interpretation of findings and critically revised the article for important intellectual content.

Medical Decision Making

Overestimation of survival rates of cardiopulmonary resuscitation is associated with higher preferences to be resuscitated: evidence from a national survey of older adults in Switzerland

Journal:	*Medical Decision Making*
Manuscript ID	MDM-23-267.R1
Manuscript Type:	Brief Report
APPLICATION AREAS:	End of life care < ETHICS, Strengthening Health Systems < GLOBAL HEALTH, HEALTH LITERACY
DETAILED METHODOLOGY:	Population based studies < CLINICAL RESEARCH METHODOLOGY, Shared Decision Making < DECISION AIDS--TOOLS, Health Literacy < JUDGMENT AND DECISION PSYCHOLOGY, Logistic Regression Models < STATISTICAL METHODS

Overestimation of survival rates of cardiopulmonary resuscitation is associated with higher preferences to be resuscitated: evidence from a national survey of older adults in Switzerland

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Complementary information

The work was done at the Swiss Centre of Expertise in the Social Sciences (FORS) at the University of Lausanne. The work was presented on a poster at the ACP-I 2023 conference in Singapore. The work is funded[1] by the Swiss National Science Foundation with the project: "Healthy Ageing in the Face of Death: Preferences, Communication, Knowledge, and Behaviors Regarding End of Life and End-of-life Planning Among Older Adults in Switzerland (grant number: 10001C_188836)". The total word counts are 1,483.

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[1] Financial support for this study was provided entirely by a grant from the Swiss National Science Foundation (SNSF). The funding agreement ensured the authors' independence in designing the study, interpreting the data, writing, and publishing the report.

Background:

Many widely used advance directives templates include direct questions on individuals' preferences for cardiopulmonary resuscitation (CPR) in case of decision-making incapacity during medical emergencies. However, as knowledge of the survival rates of CPR is often limited, individuals' advance decisions on CPR may be poorly aligned with their preferences if false beliefs about the survival rates of CPR shape stated preferences for CPR.

Methods:

We analyzed nationally representative data from 1,469 adults aged 58+ who responded to wave 8 (2019/2020) of the Swiss version of the Survey on Health, Ageing, and Retirement in Europe (SHARE) to assess the partial association between knowledge of CPR survival rates and stated preferences for CPR using multivariable probit regression models that adjust for social, health, and regional characteristics. Knowledge of CPR survival rates was assessed by asking how likely it is in general in Switzerland for a 70-year-old to survive until hospital discharge from a CPR performed outside of a hospital. Preferences for CPR were measured by asking respondents if they would wish to be resuscitated in case of cardiac arrest.

Results:

Only 9.3% of respondents correctly assessed the chances for a 70-year-old to survive until hospital discharge from a CPR performed outside of a hospital, while 65.2% indicated a preference to be resuscitated in case of a cardiac arrest. Respondents who correctly assessed CPR survival were significantly more likely to wish not to be resuscitated (AME: 0.18, $p < 0.001$).

Conclusions:

Reducing misconceptions concerning the survival rates of CPR could change older adults' preferences for CPR and make them more likely to forgo such treatments.

Highlights

- Many older adults in Switzerland overestimate the survival rates of cardiopulmonary resuscitation (CPR).
- The study reveals that individuals with accurate knowledge of CPR survival rates are more likely to refuse resuscitation in case of cardiac arrest.
- Overestimation of CPR survival rates may lead to a mismatch between individuals' preferences for CPR and their actual end-of-life care decisions.
- Improving the general population's knowledge of CPR survival rates is crucial to ensure informed decision-making and effective advance care planning.

Introduction

Increasing lifespans and improvements in medical technologies have led to major changes in the social and medical contexts in which death occurs [1,2]. The end of life and death are now more predictable, and as a result, it is increasingly important for individuals to communicate their preferences for end-of-life care in case they become unable to make decisions themselves [3,4]. Decisions regarding life-supporting treatment in advance directive forms commonly include questions on preferences for cardiopulmonary resuscitation (CPR), asking individuals to indicate whether they would like to be resuscitated in case of cardiac arrest [5,6]. In Switzerland, the survival rate for a 70-year-old after a CPR outside of a hospital is lower than 8% [7,8]. However, CPR survival rates are often overestimated in the general population [9,10], which might skew individuals' decisions toward CPR and result in poor alignment between their advance directives and actual end-of-life care preferences [11], especially as many people appear to be relatively critical with regard to potential "overtreatment" in case of medical emergencies [12,13]. Previous studies focusing on patients showed that those who received correct information on actual CPR survival rates were more likely to refuse to be resuscitated in case of a cardiac arrest [14–17]. Despite a few studies that describe the lack of knowledge of CPR survival rate and its potential association with patients' preferences for CPR [14–17], little is known about this association outside of the clinical settings. To fill this knowledge gap, we used nationally representative data on adults aged 58 years and older in Switzerland to explore the association between preferences to be resuscitated in case of cardiac arrest and knowledge of CPR survival rates.

Methods

Study design and participants

We used data of individuals who answered a Switzerland-specific self-administered paper-and-pencil questionnaire as part of wave 8 of the Survey on Health, Ageing, and Retirement in Europe (SHARE) [18]. Data collection took place between October 2019 and the beginning of March 2020. In total, 2,005 target respondents and their partners participated in the in-person interview of SHARE wave 8 in Switzerland, of which 1,891 (94,3%) also completed the national paper-and-pencil questionnaire. As the SHARE sample of individuals aged 50 and older in Switzerland was last refreshed in 2011, our current sample does not include target individuals aged 50-57 years anymore. We, therefore, only focus on respondents aged 58 and older and drop partners of target respondents below age 58. After also excluding respondents with missing responses on variables used in the analysis, the final number of respondents in our sample consisted of 1,469.

Outcome variable

Preference for CPR. Respondents' preference for CPR was assessed based on a hypothetical question (Appendix 1): *Imagine that you experience a cardiac and/or respiratory arrest. In this situation, do you wish to be resuscitated or not to be resuscitated (0=refuse CPR, 1=accept CPR)*?

Exposure

Respondents' knowledge of CPR survival rate. The questionnaire included a vignette that asked respondents to estimate how likely it is for a 70-year-old citizen in Switzerland to survive until hospital discharge after an out-of-hospital CPR following a cardiac arrest (Appendix 1). The participant could choose among four possible answers (very unlikely (0-25%), rather unlikely (26-50%), rather likely (51-75%), and very likely (76-100%)).

Covariates

Building on a seminal work investigating the end-of-life medical preferences of older adults in Switzerland [19], our statistical models include information on sex (male, female), age (58-64 years, 65-74 years, 75+ years), education levels (low= ISCED levels 0-1-2, middle= ISCED levels 3-4, high= ISCED levels 5-6 [20]), partnership status (has a partner, has no partner), subjective financial difficulties (ability to make ends meet: easily, fairly easily, and with difficulty), Switzerland's linguistic regions (German, French, or Italian), living area (urban, rural), self-rated health (poor/fair health, good health, very good/excellent health), and activities of daily living limitations (no, yes).

Statistical analysis

The distribution of preferences for CPR and knowledge of CPR survival rates were calculated using weighted proportion estimation with corresponding 95% confidence intervals. To calibrate the sample and obtain estimates representative of the target population of older adults aged 58 and older, we used the cross-sectional weights available in the SHARE dataset [21]. The partial associations between preferences for CPR and knowledge of CPR survival rates were assessed using unweighted multivariable probit regression models adjusting for the above-mentioned individuals' social, health, and regional characteristics. Two separate probit regression models were run, one with knowledge of CPR survival rates as a binary variable (right answer, wrong answer) and the other with the four possible answer variables (very unlikely (0-25%), rather unlikely (26-50%), rather likely (51-75%), and very likely (76-100%)). All estimations used STATA/SE 17.0 software (STATA Corporation, College

Station, TX), and results were reported as average marginal effects (AME) along with corresponding standard errors (SE) clustered at the household level.

Results

The characteristics of the study population are presented in Appendix 2. Figure 1 shows the weighted distribution of preference for CPR and knowledge of survival rates. In our sample, 65.2% of respondents wished to be resuscitated in case of a cardiac arrest, while only 9.3% of respondents correctly stated that it is very unlikely (0-25%) in general in Switzerland for a 70-year-old to survive until hospital discharge from a CPR performed outside of a hospital following a cardiac arrest.

The partial associations of preference for CPR with knowledge of CPR survival rates are presented in Table 1, adjusting for social, regional, and health factors. Additional information about the associations between the covariates and the outcome variables can be found in Appendix 3. Respondents who correctly estimated the CPR survival rate were significantly more likely not to want to be resuscitated in case of a cardiac and/or respiratory arrest (AME: 0.18, $p < 0.001$). In addition, when regressing preferences for CPR on stated beliefs regarding CPR survival as measured by all four possible categories, respondents who reported that CPR survival would be “rather likely” (51-75%) and “very likely” (76-100%) were significantly less likely to refuse CPR for themselves (AME: -0.23, $p < 0.001$ and AME: -0.22, $p < 0.001$). The two probit analyses conducted to validate the robustness of our findings revealed consistent outcomes across both models. In each model, individuals who correctly assessed the likelihood of surviving CPR were more inclined to opt against resuscitation. Furthermore, the second probit regression indicated that the association was statistically significant only for individuals who estimated the CPR survival rate to be higher than 50%.

Discussion

Using a population-based sample of 1,469 adults aged 58 years and older living in Switzerland, we investigated the association between preferences to be resuscitated in case of cardiac arrest and knowledge of general CPR survival rates assessed via a survey vignette. Most respondents (65.2%) wished to be resuscitated in case of cardiac arrest and overestimated (90.7%) the probability for a 70-year-old to survive until hospital discharge from a CPR performed outside of a hospital. In addition, respondents who overestimated CPR survival rates were statistically significantly more likely to want to be resuscitated in case of cardiac arrest.

Only 9.3% had reasonably accurate perceptions of these CPR survival rates. More accurate perceptions of CPR survival rates are positively associated with refusal of CPR, consistent with results of a comparable study on older patients in a clinical setting [17]. More accurate perceptions of CPR survival rates, which are much lower than usually perceived, could influence older adults' preference for CPR and corresponding choices in potential advance directives. Similar findings have also been obtained in earlier intervention studies [14–16] that directly provided patients with information about the probability of CPR survival before asking for their preferences. In these studies, most respondents did not want to undergo CPR once healthcare providers explained to them the probability of survival.

Unrealistic expectations of CPR survival may also require healthcare providers to manage disappointment of patients and their families when discussing actual chances of survival following CPR [22]. Healthcare providers often report the struggle to initiate CPR discussions knowing that the topic is emotionally difficult for patients and depends on patients' evolution of their prognoses, which is hard to predict [23]. Improving individuals' knowledge of CPR survival rates could facilitate discussions with healthcare providers and potentially affect treatment preferences by mitigating unrealistic expectations [24]. Moreover, the fact that most people overestimate the chances of survival of CPR strongly supports an advance care planning process that would include medical expertise on prognosis, for instance, in the form of CPR decision aids [25].

Limitations

A primary limitation of our study is the phrasing of the resuscitation question, which did not provide alternatives such as comfort measures. This might have inclined participants towards CPR, potentially perceiving it as the only option against abandonment, thereby potentially overestimating the overall preference for resuscitation. Furthermore, using qualitative and quantitative labels for the answer categories in the question on knowledge of CPR survival rates could have confused some respondents. In addition, the concepts of probability may be hard to understand for some respondents, even though probabilistic questions have been successfully used in SHARE for quite some time. Similarly, problems of study enrollment, attrition and missing data may create a sample selection bias and underrepresentation of especially vulnerable segments of the population.

Conclusion

Most older adults in Switzerland wish to be resuscitated in case of cardiac arrest, but those with more accurate beliefs regarding CPR survival rates are more likely to prefer not to be resuscitated in case of a cardiac arrest. The overestimations of CPR survival rate may result in patients and families choosing to be resuscitated in case of a cardiac arrest due to over-optimistic beliefs regarding the likelihood of surviving CPR, which could compromise the quality and reliability of advance care planning. Therefore, it is necessary to improve the general population's knowledge of the CPR survival rate and inform the healthcare providers of the importance of discussing this treatment and its consequences in detail with their patients.

Conflict of interest

The authors declare that they have no competing interests.

Ethical approval

Our study obtained ethical approval number 66/14 from the ethics committee of the canton of Vaud, Switzerland, in March 2014.

Data sharing statement

This paper uses data from Börsch-Supan, A. (2022). Survey of Health, Ageing and Retirement in Europe (SHARE) Wave 8. Release version: 1.0.0. SHARE-ERIC. Data set. DOI: 10.6103/SHARE.w8.100. Study data already de-identified are available to the scientific community upon submitting a data requestion application to the SHARE study.

Financial disclosure

SNSF funding for the end-of-life project. Healthy Ageing in the Face of Death: Preferences, Communication, Knowledge, and Behaviors Regarding End of Life and End-of-life Planning Among Older Adults in Switzerland (grant number: 10001C_188836).

This paper uses data from SHARE Waves 8 (10.6103/SHARE.w8.800) see Börsch-Supan et al. (2013) for methodological details.(1) The SHARE data collection has been funded by the European Commission, DG RTD through FP5 (QLK6-CT-2001-00360), FP6 (SHARE-I3: RII-CT-2006-062193, COMPARE: CIT5-CT-2005-028857, SHARELIFE: CIT4-CT-2006-028812), FP7 (SHARE-PREP: GA N°211909, SHARE-LEAP: GA N°227822, SHARE M4: GA N°261982, DASISH: GA N°283646) and Horizon 2020 (SHARE-DEV3: GA N°676536, SHARE-COHESION: GA N°870628, SERISS: GA N°654221, SSHOC: GA N°823782, SHARE-COVID19: GA N°101015924) and by DG Employment, Social Affairs & Inclusion through VS 2015/0195, VS 2016/0135, VS 2018/0285, VS 2019/0332, and VS 2020/0313. Additional funding from the German Ministry of Education and Research, the Max Planck Society for the Advancement of Science, the U.S. National Institute on Aging (U01_AG09740-13S2, P01_AG005842, P01_AG08291, P30_AG12815, R21_AG025169, Y1-AG-4553-01, IAG_BSR06-11, OGHA_04-064, HHSN271201300071C, RAG052527A) and from various national funding sources is gratefully acknowledged *(see https://share-eric.eu)*.

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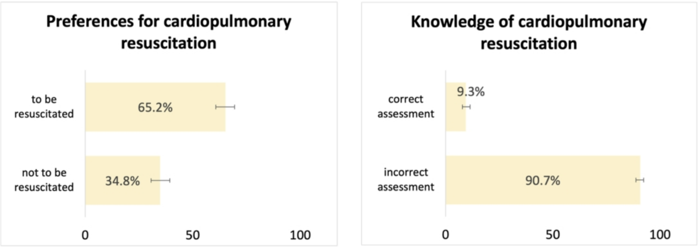
Table 1 Partial associations of preference for cardiopulmonary resuscitation on knowledge of survival rates controlling for respondents' social, cultural, and health characteristics, adults aged 58+, SHARE Switzerland, 2019/2020, n=1,469

	Preference not to be resuscitated (AME)	Preference not to be resuscitated (AME)
Gave the correct assessment (gave the incorrect assessment)	0.18^{***} (0.04)	
Likelihood of surviving from cardiopulmonary resuscitation (Very unlikely (0-25%))		
Rather unlikely (26-50%)		-0.08 (0.04)
Rather likely (51-75%)		-0.23^{***} (0.04)
Very likely (76-100%)		-0.22^{***} (0.05)

*The table shows average marginal effects and standard errors in parentheses from separate models. Statistical significance: * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$. The two probit regression models control for sex, age, education levels, partnership status, subjective financial situation, linguistic region, living area, self-rated health, and ADL limitations.*

Figure 1: Preferences for cardiopulmonary resuscitation and knowledge of survival rates, weighted proportions and 95% confidence intervals, adults aged 58+, SHARE Switzerland, 2019/2020, n=1,469



The figures present the weighted distribution of preferences for cardiopulmonary resuscitation and knowledge of survival rates.

Figure 1/Preferences for cardiopulmonary resuscitation and knowledge of survival rates, weighted proportions and 95% confidence intervals, adults aged 58+, SHARE Switzerland, 2019/2020, n=1,469

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Appendices

Appendix 1: CPR questions used in the analysis

Question 1: Imagine that you experience a cardiac and/or respiratory arrest. In this situation, you wish ...

Answer categories: "**to be** resuscitated", " **not to be** resuscitated"

Question 2: People have representations of end-of-life medical situations. We would like to know yours. We would like to know whether you think that the situations described below and related to end-of-life are very unlikely (0-25%), rather unlikely (26-50%), rather likely (51-75%) or very likely (76-100%).
If you don't know, please give us your best estimate. *Example: "In your opinion, what are the chances that it is snowing tomorrow?" If you tick "very likely", you consider that the chances that it is snowing tomorrow range between 76% and 100%.*

In your opinion, how likely is it **in general in Switzerland** for a 70-year-old to survive until hospital discharge from a cardiopulmonary resuscitation performed outside of a hospital following a cardiac arrest?

Answer categories: "very unlikely (0-25%)", "rather unlikely (26-50%)", "rather likely (51-75%)", "very likely (76-100%)"

Appendix 2: Characteristics of the study population, adults aged 58+, SHARE Switzerland, 2019/2020, n=1,469

	Unweighted	Weighted	
	n	%	CI
Sex			
male	699	53.0	[48.5-57.4]
female	770	47.0	[42.6-51.5]
Age groups			
58-64 years	370	50.9	[45.7-56.0]
65-74 years	631	27.9	[24.7-31.4]
75+ years	468	21.2	[18.6-24.1]
Education			
low	237	14.2	[11.4-17.7]
middle	944	64.9	[60.1-69.5]
high	288	20.9	[16.9-25.4]
Partnership status			
has a partner	1,112	70.7	[65.8-75.1]
no partner	357	29.3	[24.9-34.2]
Make ends meet			
easily	817	57.7	[52.8-62.4]
fairly easily	468	30.2	[26.0-34.8]
with difficulty	184	12.1	[9.3-15.6]
Language			
German	1,064	73.0	[68.1-77.4]
French	352	24.2	[19.8-29.0]
Italian	53	2.9	[2.0-4.2]
Living area			
urban	666	40.9	[36.1-45.9]
rural	803	59.1	[54.1-63.9]
Self-rated health			
poor/fair health	266	16.1	[13.0-19.7]
good health	617	39.5	[34.8-44.4]
Very good/excellent health	586	44.4	[39.3-49.7]
ADL limitations			
no	1,378	94.2	[91.7-96.0]
yes	91	5.8	[4.0-8.3]
Preferences for CPR			
to be resuscitated	873	65.2	[60.7-69.4]
not to be resuscitated	596	34.8	[30.6-39.3]
Knowledge of CPR			
incorrect assessment	1,288	90.7	[88.7-92.3]
correct assessment	181	9.3	[7.7-11.3]

Note, unweighted and weighted number of observations for the whole sample. n = number; CI = confidence interval; ADL = activities of daily living limitations.

Appendix 3: Partial associations of preference for cardiopulmonary resuscitation on knowledge of survival rates controlling for respondents' social, cultural, and health characteristics, adults aged 58+, SHARE Switzerland, 2019/2020, n=1,469

	Preference not to be resuscitated (AME)	Preference not to be resuscitated (AME)
Gave the correct assessment (gave the incorrect assessment)	0.18*** (0.04)	
Likelihood of surviving from cardiopulmonary resuscitation (Very unlikely (0-25%))		
Rather unlikely (26-50%)		-0.08 (0.04)
Rather likely (51-75%)		-0.23*** (0.04)
Very likely (76-100%)		-0.22*** (0.05)
Sex (male)		
female	0.11*** (0.02)	0.11*** (0.02)
Age groups (58-64 years)		
65-74 years	0.10** (0.03)	0.10** (0.03)
75+ years	0.19*** (0.03)	0.19*** (0.03)
Education (low)		
middle	-0.02 (0.04)	-0.01 (0.03)
high	-0.11* (0.04)	-0.10* (0.04)
Partnership status (has a partner)		
no partner	0.08* (0.03)	0.07* (0.03)
Make ends meet (easily)		
fairly easily	-0.02 (0.03)	-0.02 (0.03)
with difficulty	-0.05 (0.04)	-0.05 (0.04)
Language (German)		
French	0.07* (0.03)	0.08** (0.03)
Italian	-0.26*** (0.04)	-0.26*** (0.04)
Living area (urban)		
rural	-0.01 (0.03)	-0.01 (0.03)
Self-rated health (poor/fair health)		
good health	-0.10** (0.04)	-0.09* (0.04)
very good/excellent health	-0.12** (0.04)	-0.11** (0.04)
ADL limitations (no)		
yes	0.02 (0.05)	0.01 (0.05)
Observations	1469	1469

*The table shows average marginal effects and standard errors in parentheses from separate models. Statistical significance: * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.*

4.4 Article IV

Title: Development and validation of a subjective end-of-life health literacy.

Authors: Clément Meier, Dr. Sarah Vilpert, Dr. Maud Wieczorek, Dr. Carmen Borrat-Besson, Prof. Ralf J. Jox and Prof. Jürgen Maurer

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RESEARCH ARTICLE

Development and validation of a subjective end-of-life health literacy scale

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Abstract

Personal health literacy is the ability of an individual to find, understand, and use information and services to inform health-related decisions and actions for oneself and others. The end of life is commonly characterized by the occurrence of one or several diseases, the use of many different types of healthcare services, and a need to make complex medical decisions that may involve challenging tradeoffs, such as choices between quality and length of life. Although end-of-life care issues concern most people at some point in life, individuals' competencies to deal with those questions have rarely been explored. This study aims to introduce, develop, and validate an instrument to measure individuals' self-assessed competencies to deal with end-of-life medical situations, the Subjective End-Of-Life Health Literacy Scale (S-EOL-HLS), in a sample of older adults aged 50+ living in Switzerland who participated in wave 8 (2019/2020) of the Survey of Health, Ageing, and Retirement in Europe. The S-EOL-HLS uses a series of questions on self-rated difficulties in understanding end-of-life medical jargon, defining in advance which end-of-life medical treatments to receive or refuse, and communicating related choices. Aside from conducting exploratory and confirmatory factor analysis to evaluate the construct validity, we compared measurements from the S-EOL-HLS to respondents' general health literacy measured with the European Health Literacy Survey questionnaire. We obtained a three-factor model with acceptable fit properties (CFI = 0.993, TLI = 0.992, RMSEA = 0.083, SRMR = 0.061) and high reliability (α = 0.93). The partial associations between the health literacy scores from the two scales and respondents' sociodemographic characteristics were similar; however, individuals with higher end-of-life health literacy scores appeared to have more positive attitudes towards end-of-life care planning outcomes. The S-EOL-HLS demonstrates reliable and consistent results, making the instrument suitable for older adults in population surveys.

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Introduction

Personal health literacy, that is, "the degree to which individuals can find, understand, and use information and services to inform health-related decisions and actions for themselves and others" [1], is commonly seen as a crucial factor in enabling patients' autonomy, improving their satisfaction and achieving better health and healthcare outcomes [2]. By acquiring health literacy skills, individuals can make healthier lifestyle choices, seek more appropriate healthcare services, and empower themselves to deal with illness [3, 4]. Health literacy skills hold particular importance in aging populations where chronic diseases are more prevalent [5]. These skills are essential due to the frequent need for complex treatment regimes, especially in cases of multimorbidity [5]. Health literacy significantly influences how individuals perceive their health challenges, communicate with healthcare providers, and make medical decisions [6].

Health and healthcare decision-making regarding the end of life, such as the completion of advance directives or the engagement in advance care planning, can be especially challenging for individuals as they have to make anticipatory decisions for hypothetical scenarios that may involve complex tradeoffs between quality and quantity of life and that frequently take place in emotionally-charged situations with potentially difficult family dynamics and interactions [7–9]. End-of-life health literacy is likely to be distinct from general health literacy due to the particular skills needed to navigate specific challenges of end-of-life planning and decision-making, such as exceptionally high stakes (questions of life and death), increased levels of risk and uncertainty, major emotional challenges related to the family and social contexts of dying, and complex discussions with highly-specialized professionals, potentially in a context of deteriorating physical and/or mental capacities. Poor end-of-life health literacy can lead to fewer palliative care visits, lack of advance care planning and advance directive completion, worse health status, lower quality of life at the end of life, and higher rates of unnecessary hospitalizations [10–12]. Improving health literacy related to end-of-life decision-making can thus support patient engagement and empowerment to make their own decisions in the face of death and potentially result in improved outcomes related to death and dying [13, 14].

Before delving into the specifics of our study, it's pertinent to shed light on some region-specific factors within Switzerland, the country where our research was conducted. The legal status of advance directives in Switzerland has been firmly established since 2013, when the Swiss Federal Council acknowledged their importance and introduced a new adult protection law into the Swiss Civil Code [15]. This significant legislative step amplified public awareness around end-of-life planning, however, despite this new law and the general growth of interest regarding end-of-life issues and palliative care, research indicates that the proportion of the general population completing advance directives remains relatively low [16]. Furthermore, it is crucial to acknowledge Switzerland's significant linguistic diversity, with the country partitioned into three main regions: German, French, and Italian. Differences across these regions are often observed, notably in the varying preferences, attitudes, and behaviors related to end-of-life care and planning [16, 17].

Even though end-of-life care issues concern every person, little research has explored the level of health competencies that individuals have for this life stage. So far, existing studies have shown that patients' knowledge of end-of-life care options is rather limited [18, 19], which may at least partly reflect limited competencies to deal with end-of-life medical situations. Recent population-based studies have highlighted significant knowledge gaps regarding end-of-life care options as well as considerable variation in the perceptions of medical end-of-life situations [20, 21]. In addition, the ACP Engagement Survey was developed to measure the complex process of advance care planning by asking questions on surrogate decision-making, value, and quality of life, and on communication with medical providers; the results ultimately showed that engagement in advance care planning remains low among older patients [22]. Other research focusing on so-called "death literacy," a concept related to individuals' skills and knowledge regarding the death system, such as factual knowledge, learning experience, emotional support, hands-on care, or community capacity, suggests that higher death literacy could help individuals make better-informed decisions regarding end-of-life and death care options [23]. While the concept of death literacy encompasses knowledge and skills related to understanding and navigating the death system, it does not specifically address individual's ability to navigate medical decisions at the end of life. Yet, to the best of our knowledge, there is no specific survey instrument to measure end-of-life health literacy in view of the distinct challenges of end-of-life decision-making relative to more general decision-making challenges concerning health and healthcare.

Building on existing international end-of-life research [24] and corresponding evidence from Switzerland [25], our study had three distinct aims.

- First, we aimed to introduce the conceptual basis and the development of a new survey scale—the Subjective End-Of-Life Health Literacy Scale (S-EOL-HLS)—to measure the level of competencies individuals perceive to have in dealing with end-of-life care situations.
- Our second aim was to assess the reliability and construct validity of the new instrument with both exploratory and confirmatory factor analysis in a sample of older adults aged 50+ in Switzerland.
- Finally, our last objective was to compare the respective associations between individuals' social, regional, and health characteristics and the scores from the S-EOL-HLS and from the validated European Health Literacy Survey questionnaire (HLS-EU-Q16). We further checked the discriminant ability of these two instruments with regard to end-of-life care planning outcomes.

Methods

Conceptual framework and development of the survey instrument

Conceptual framework. The proposed S-EOL-HLS aims to measure individuals' self-perceived end-of-life health literacy skills for advance care planning and end-of-life decision-making. To this end, the instrument aims to measure individuals' subjective ease (1) in comprehending vocabulary that is commonly used in advance care planning and discussions of end-of-life care (functional health literacy); (2) to effectively engage, interact and apply newly-acquired information in discussions with healthcare providers and family concerning advance care planning and end-of-life care (interactive health literacy) and (3) using relevant end-of-life-related information and advice to form and express informed end-of-life decisions that are aligned with the individuals' preferences and values, including potential advance end-of-life decisions as required by advance care planning or when using advance directives (critical health literacy). The conceptual distinction between functional, interactive, and critical health literacy as three key hierarchical layers of general health literacy was first explained in the seminal work of Nutbeam (2000) [26], and was adapted by Ladin et al. (2018) [27] to (advance) end-of-life care decision-making in order to assess health literacy gaps for end-of-life planning among older dialysis patients in the United States. Specifically, Nutbeam's general health literacy framework conceptualizes functional health literacy as individuals' abilities to read and write effectively in everyday situations; interactive health literacy as more advanced skills to participate actively in daily activities to extract and apply information from various forms of communication; and critical health literacy as an even higher level of skills regarding how individuals critically analyze information to make informed decisions.

Development of the survey instrument. Following Nutbeam's framework and using its adaptation to end-of-life health literacy proposed by Ladin et al. (2018) [27], we developed a series of survey items aimed at measuring functional, interactive, and critical health literacy pertaining to end-of-life care decision-making with a focus on critical health literacy skills for the completion of advance directives as key tools of advance care planning in both clinical settings and more broadly, in the general population (S1 Fig).

In general, health literacy can be assessed by subjective or objective (often test-based) measures [28]. These two approaches are often considered complementary, as they capture distinct aspects of health literacy and have each different practical advantages and disadvantages concerning measurement across different settings [28]. Objective test-based measures of health literacy, such as the Test of Functional Health Literacy in Adults (TOFHLA) or the National Assessment of Adult Literacy (NAAL) [29, 30], aim at quantifying individuals' health literacy skills by subjecting them to standardized test stimuli, which measure whether individuals can accurately perform a specific task. While such objective test-based measures of health literacy provide directly comparable measurements of a person's skill in a prespecified domain and do not suffer from issues of differential item functioning, one common limitation of these measures is that they tend to be domain-specific and may, therefore not be easily generalizable to different contexts. In addition, objective test-based measures typically require standardized conditions, thus excluding collaboration with other individuals, which makes such tests easier to administer in-person than, say, in the context of a paper and pencil mail or drop-off survey. Finally, "testing" individuals for their health literacy skills may result in high response burden in terms of required survey time, cognitive effort, and risk for stigma, which makes it challenging to include such assessments in larger-scale longitudinal general-purpose surveys in which considerations of interview time and risk of attrition are often paramount [28]. On the other hand, subjective health literacy measures typically ask individuals to rate their perceived difficulties with different types of health literacy tasks on a Likert or other rating scale. While such measures lack fully-standardized test stimuli and may suffer from differential item functioning, they are also often easier and more rapid to administer, especially in the context of a drop-off survey, less stigmatizing for individuals with lower health literacy, and easily adaptable to a broad range of situations. Subjective measures of health literacy have a notable connection with the concept of self-efficacy in health literacy tasks [31–33]. This connection makes the measurement of subjective health literacy interesting. Specifically, individuals' judgments of their capabilities to execute specific health literacy tasks—i.e., self-efficacy—may be a significant determinant of health behaviors, healthcare use, and related outcomes [34]. Subjective health literacy may thereby be especially important in the context of advance care planning and end-of-life care due to the special challenges posed by such planning and the high importance of individuals' own initiative for engaging in such planning. Subjective health literacy measures such as the European Health Literacy Survey questionnaire (HLS-EU) or the Health Literacy Questionnaire (HLQ) are, therefore, used as important complements to objective test-based measures. Developing subjective health literacy measures specifically for advance care planning and end-of-life decision-making holds major promise to improve our understanding of individuals' engagement in these processes.

Following the approach of other subjective assessments of general health literacy, such as the HLS-EU, we designed several questions (S1 Fig) to assess self-rated/subjective (a) functional end-of-life health literacy (understanding specialized vocabulary items); (b) interactive health literacy (feel comfortable items); (c) critical health literacy (treatment preference items). All items were rated using an identical four-point Likert scale with the answer categories "very easy," "fairly easy," "fairly difficult," and "very difficult," corresponding to the rating scales used in the HLS-EU and other subjective health literacy assessment tools [35–37]. Specifically, functional end-of-life health literacy (1) is measured by six items assessing self-rated difficulties in *understanding* medical terms that are relevant to end-of-life decision-making (prognosis, intubation, palliative care, cardiopulmonary resuscitation, artificial nutrition, and sedation). Seven items measure interactive end-of-life health literacy; the first three elicit respondents' self-rated difficulties in talking about their end-of-life preferences with someone they trust, such as a close family member or friend; self-rated difficulties in talking to a physician or other medical expert to learn more about advance care planning tools and end-of-life treatments; and self-rated difficulties in finding/obtaining information and/or obtain template forms to complete a so-called "advance directives." The next four items are related to how individuals apply the new information; they measure respondents' self-rated difficulties in defining what "overtreatment" means to them, making decisions on whether to accept a treatment or not based on probabilities of different treatment outcomes, choosing between comfort care (relieving suffering without slowing the disease) and aggressive life-prolonging treatment (heavy chemotherapy, intensive care with artificial ventilation) should they suffer from a terminal disease; and defining specific conditions or situations in which they would prefer to be left to die. Critical end-of-life health literacy is assessed by five items measuring individuals' self-rated difficulties if they had to decide (at the time of the interview) whether they wish to receive or refuse five potential treatments at the end of life (breathing machines, artificial nutrition, blood transfusion, antibiotics, cardiopulmonary resuscitation), which correspond to commonly used "tick box items" in various advance directive forms/templates proposed by different organizations and institutions.

Face and content validity of the S-EOL-HLS was established through an iterative discussion and revision process involving the entire multidisciplinary project team composed of experts in sociology and psychology of health, public health, palliative care, end of life, and survey research. We also conducted six in-depth cognitive interviews with adults aged 50 and over to identify and correct potential confusion or inconsistency in question understanding, lack of clarity, and specificity in question-wording. Finally, our instrument was first distributed to a pilot sample of 123 respondents representing our target population of older adults in Switzerland to analyze potential response biases before being administrated to the entire Swiss SHARE sample.

Validation/psychometric assessment of the instrument

Study design and participants. We used data from wave 8 of the Swiss component of the Survey of Health, Ageing, and Retirement in Europe (SHARE) [38]. Every two years, SHARE collects longitudinal information on health, socioeconomic status, and social or family network from Europeans aged 50 years and older and their partners. The study began in 2004 with random representative samples of older individuals in each of the ten participating countries, including Switzerland. SHARE now includes 27 European countries and Israel. During each survey round, respondents give their verbal informed consent to participate in SHARE twice: once when they accept to schedule a personal interview after a phone call from the interviewer and then again at the beginning of the face-to-face interview. The SHARE data combines internationally-harmonized face-to-face Computer-Assisted Personal Interviewing (CAPI) interviews and national self-administered paper-and-pencil questionnaires completed by the respondents after the main in-person interview. Our study includes data from the Swiss self-administered national questionnaire on end-of-life issues, which was issued during SHARE wave 8 (2019/2020) in Switzerland, and sociodemographic variables obtained from the main SHARE interview. In March 2014, the Ethics Committee of the Canton of Vaud, Switzerland, granted our study the ethical approval, bearing the number 66/14. Overall, 2,005 Swiss respondents participated in Wave 8 of SHARE between October 2019 and the beginning of March 2020 (pre-COVID-19 measures). Among them, 1,891 individuals also completed the Swiss self-administrated questionnaire (a 94,3% cooperation rate). After excluding respondents with missing item responses on any variable included in our analysis, our final analytical sample contains 1,270 participants.

Outcome variables. *Subjective End-Of-Life Health Literacy Scale (S-EOL-HLS)*. The S-EOL-HLS contains 18 items (S1 Table) aimed at measuring functional, interactive, and critical health literacy pertaining to end-of-life care decision-making and skills for completing advance directives. Following the approach used by the HLS-EU consortium, the final end-of-life health literacy score is calculated as the percentage of items that were answered with "very easy" or "easy": (Number of "very easy" or "easy" responses / 18) x 100. The scale thus ranged from 0 to 100.

HLS-EU-Q16. The short version of the European Health Literacy Survey questionnaire developed by the HLS-EU consortium was also part of our Swiss paper-and-pencil questionnaire to capture our respondents' self-assessed general health literacy and compare it to the more specific concept of end-of-life health literacy. The HLS-EU scale contains 16 items (S2 Table) with which individuals rate their health literacy with regard to four stages of information processing, i.e., accessing/obtaining health information, understanding health information, processing/appraising health information, applying/using health information, and three domains, i.e., healthcare, disease prevention, health promotion. Each item includes concrete health-relevant tasks or situations whose perceived difficulty respondents rate on a 4-point Likert scale with answers ranging from "very easy," "fairly easy," "fairly difficult," to "very difficult." The final health literacy score is calculated as the percentage of items that were answered with "very easy" or "easy": (Number of "very easy" or "easy" responses / 16) x 100. The scale thus ranged from 0 to 100.

Independent variables. Our regression models include information about gender (0 = male, 1 = female), age group (50–64 years, 65–74 years, 75+ years), and education level, which was divided into three categories based on the International Standard Classification of Education (ISCED) of 2017 [39] (low = ISCED levels 0-1-2, middle = ISCED levels 3–4, high = ISCED levels 5–6). Our study looked at all types of partnerships rather than just focusing on legal marriage (0 = has a partner, 1 = has no partner). Based on the question: "Is your household able to make ends meet?" respondents' perceptions of their financial situation were recoded into three categories (1 = easily, 2 = fairly easily, 3 = with difficulty). We also included information on which of the three linguistic regions of Switzerland the respondents lived in, depending on the language they used to answer the questionnaire (German, French, or Italian), as well as if they lived in an urban or rural area (0 = urban, 1 = rural). Finally, we controlled for respondents' self-rated health status and recoded the outer categories to obtain a three-point scale (1 = poor/fair health, 2 = good health, 3 = very good/excellent health).

End-of-life health outcomes. Three variables assessing attitudes toward the end of life were also used in the analysis: whether respondents ever discussed with someone about their wishes for the end of their life (1 = yes, 2 = no), whether they have completed a written statement about their wishes and refusals for medical treatments and care (advance directives) (1 = yes, 2 = no) and whether they appointed someone in writing to make medical decisions for them should they not be able to make those decisions for themselves (1 = yes, 2 = no).

Assessment of metrics properties. We first investigated the correlation matrix of the 18 proposed end-of-life health literacy items using Pearson correlation analysis and checked the internal consistency and reliability of the items using Cronbach's alpha [40]. Using exploratory factor analysis on a randomly split-half sample (n = 635), we assessed the unrestricted factor structure of our scale to evaluate the number of factors and their respective dimensions without imposing any of the conceptual designs used during scale development [41, 42]. The exploratory factor analysis was conducted using a weighted least squares estimator and Promax rotation. Following the exploratory factor analysis, we used the second half of the sample (n = 635) for a confirmatory factor analysis to test the presumed three-domain structure of end-of-life health literacy consisting of functional, interactive, and critical end-of-life health literacy (S1 Fig) [43]. The confirmatory factor analysis used the weighted least squares mean, and variance adjusted (WLSMV) estimator that best fit the categorical and ordinal nature of the data. We compiled the root mean square error of approximation (RMSEA), standardized root means square residual (SRMR), comparative fit index (CFI), and adjusted goodness of fit index (TLI) to assess the model fit. The following cut-off values were considered as indications of an acceptable fit; RMSEA $\leq$ 0.08, SRMR $\leq$ 0.10, CFI $\geq$ 0.95, and TLI $\geq$ 0.95 [44–46]. Exploratory and confirmatory factor analyses were performed with the software packages *Psych* version 2.2.9 and *Lavaan* version 0.6–12 using R version 4.1.2.

Assessment of end-of-life subjective health literacy in the older population in Switzerland. To evaluate the construct validity of the S-EOL-HLS scale, we used OLS regression models to compare the partial associations between the S-EOL-HLS score and respondents' characteristics with those from the HLS-EU-Q16. The estimated standard errors were adjusted to account for the possibility of dependencies in the observations as both partners of the same couple may participate in our study, which increases the chances of similar responses. The regressions were hence clustered at the household level to account for such potential dependencies. In addition, we also compared the two scales' average scores for the three end-of-life care planning outcomes. We finally completed a ROC analysis and used the area under the curve to evaluate the performance of both scales on the three end-of-life planning outcomes [47]. All estimations were performed using STATA/SE 17.0 software (STATA Corporation, College Station, TX).

Results

Table 1 introduces the key characteristics of the analytical sample. Almost half of the sample were women (52%), the mean age was 70.4 years old (SD: 8.2), and the majority had a middle level of education (64%). More than three quarters of the respondents had a partner (78%), and most reported that it was "easy" (57%) or "fairly easy" (31%) to make ends meet at the end of the month. Regarding the language region, 73% lived in the German-speaking part of Switzerland, and 55% lived in a rural area. Respondents mostly reported good or excellent health (42% and 42%, respectively). Concerning the end-of-life care planning outcomes, 66% had already discussed their wishes for the end of life, 42% had completed an advance directive, and 43% had appointed someone as surrogate to make medical decisions on their behalf.

Fig 1 displays the proportion per category of answers for each end-of-life health literacy item. Most respondents seemed not to have difficulties dealing with end-of-life medical situations. The three medical terms that were most difficult to understand were "sedation" (40.9%), "intubation" (27.3%), and "palliative care" (18.6%). Respondents reported unease in various situations: 39.7% found it difficult to make decisions that involved probabilities; 34.6% struggled to define the term 'overtreatment'; 37.7% had difficulties in specifying conditions or circumstances under which they would prefer to die; and, 36.1% were uncomfortable when asked to choose a type of treatment if they were to have a terminal illness. Finally, it was also rather difficult for respondents to indicate their willingness to receive or refuse "breathing machines"

Table 1. Characteristics of the study population, adults aged 50+, SHARE Switzerland, 2019/2020, n = 1,270.

	n	%
Gender		
Male	612	48
Female	658	52
Age groups		
58–64 years	352	28
65–74 years	548	43
75+ years	370	29
Education		
Low	190	15
Middle	808	64
High	272	21
Partnership status		
Has a partner	991	78
No partner	279	22
Make ends meet		
Easily	719	57
Fairly easily	395	31
With difficulty	156	12
Linguistic regions		
German	920	73
French	308	24
Italian	42	3
Living area		
Urban	572	45
Rural	698	55
Self-rated health		
Poor/fair health	202	16
Good health	531	42
Excellent health	537	42
EOL discussion		
Yes	841	66
No	429	34
Complete ADs		
Yes	527	42
No	743	58
Appointed surrogate		
Yes	549	43
No	721	57

Note, number of observations for the whole sample. AD = Advance Diectives. EOL = End-Of-Life.

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(28.6%), "cardiopulmonary resuscitation" (30.3%), and "artificial nutrition" (30.4%) as part of their end-of-life care wishes.

The next heatplot on Fig 2 presents the Pearson correlation analysis of the S-EOL-HLS items. It shows that the items are moderately correlated with each other and show higher correlations among items that aim to measure the same aspect of end-of-life health literacy. The graph identifies the three factors present in the scale: functional end-of-life health literacy

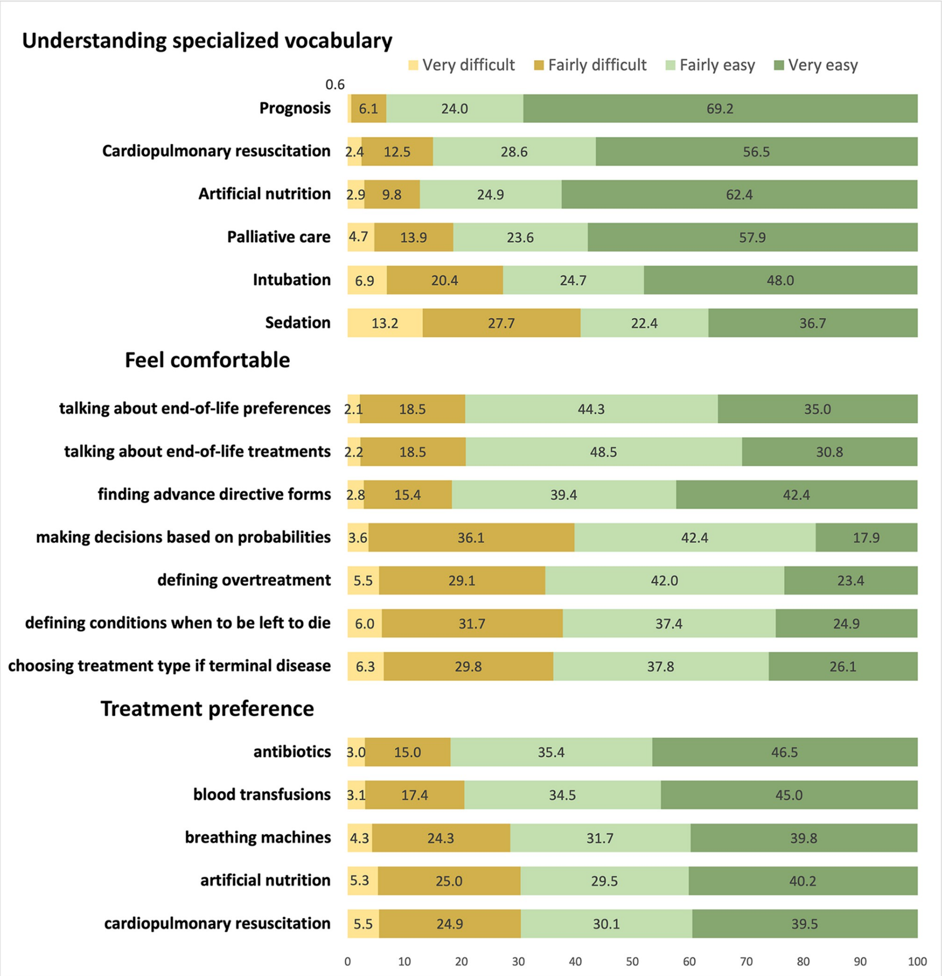

Fig 1. Subjective End-of-life Health Literacy Scale (S-EOL-HLS), percentage of respondents per categories, adults aged 50+, SHARE Switzerland, 2019/2020, n = 1,270.

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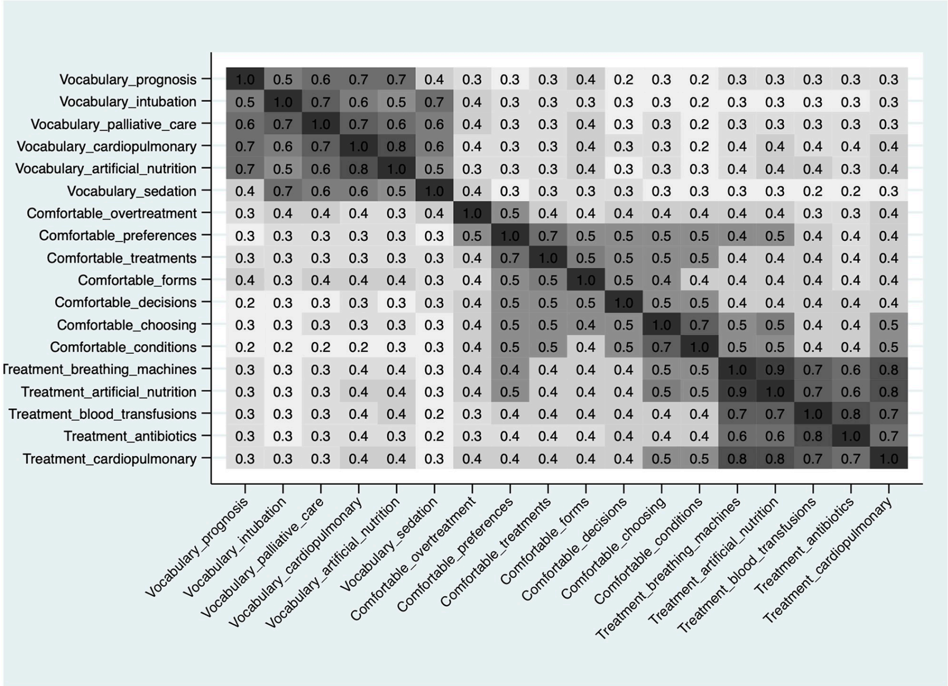
(understanding specialized vocabulary), interactive end-of-life health literacy (feel comfortable), and critical end-of-life health literacy (treatment preference). The Cronbach alphas also indicated high internal consistency and reliability for the overall instrument ($\alpha = 0.93$) as well as for each factor ($\alpha_1 = 0.9$, $\alpha_2 = 0.86$, $\alpha_3 = 0.93$).

We first examined the sampling adequacy and correlation among the items before the exploratory factor analysis. The suitability for performing factor analysis was confirmed with a



	Vocabulary_prognosis	Vocabulary_intubation	Vocabulary_palliative_care	Vocabulary_cardiopulmonary	Vocabulary_artificial_nutrition	Vocabulary_sedation	Comfortable_overtreatment	Comfortable_preferences	Comfortable_treatments	Comfortable_forms	Comfortable_decisions	Comfortable_choosing	Comfortable_conditions	Treatment_breathing_machines	Treatment_artificial_nutrition	Treatment_blood_transfusions	Treatment_antibiotics	Treatment_cardiopulmonary
Vocabulary_prognosis	1.0	0.5	0.6	0.7	0.7	0.4	0.3	0.3	0.3	0.4	0.2	0.3	0.2	0.3	0.3	0.3	0.3	0.3
Vocabulary_intubation	0.5	1.0	0.7	0.6	0.5	0.7	0.4	0.3	0.3	0.3	0.3	0.3	0.2	0.3	0.3	0.3	0.3	0.3
Vocabulary_palliative_care	0.6	0.7	1.0	0.7	0.6	0.6	0.4	0.3	0.3	0.4	0.3	0.3	0.2	0.3	0.3	0.3	0.3	0.3
Vocabulary_cardiopulmonary	0.7	0.6	0.7	1.0	0.8	0.6	0.4	0.3	0.3	0.4	0.3	0.3	0.2	0.4	0.4	0.4	0.4	0.4
Vocabulary_artificial_nutrition	0.7	0.5	0.6	0.8	1.0	0.5	0.3	0.3	0.3	0.4	0.3	0.3	0.3	0.4	0.4	0.4	0.3	0.4
Vocabulary_sedation	0.4	0.7	0.6	0.6	0.5	1.0	0.4	0.3	0.3	0.3	0.3	0.3	0.3	0.3	0.3	0.2	0.2	0.3
Comfortable_overtreatment	0.3	0.4	0.4	0.4	0.3	0.4	1.0	0.5	0.4	0.4	0.4	0.4	0.4	0.4	0.4	0.3	0.3	0.4
Comfortable_preferences	0.3	0.3	0.3	0.3	0.3	0.3	0.5	1.0	0.7	0.5	0.5	0.5	0.5	0.4	0.5	0.4	0.4	0.4
Comfortable_treatments	0.3	0.3	0.3	0.3	0.3	0.3	0.4	0.7	1.0	0.5	0.5	0.5	0.5	0.4	0.4	0.4	0.4	0.4
Comfortable_forms	0.4	0.3	0.4	0.4	0.4	0.3	0.4	0.5	0.5	1.0	0.5	0.4	0.4	0.4	0.4	0.4	0.4	0.4
Comfortable_decisions	0.2	0.3	0.3	0.3	0.3	0.3	0.4	0.5	0.5	0.5	1.0	0.5	0.5	0.4	0.4	0.4	0.4	0.4
Comfortable_choosing	0.3	0.3	0.3	0.3	0.3	0.3	0.4	0.5	0.5	0.4	0.5	1.0	0.7	0.5	0.5	0.4	0.4	0.5
Comfortable_conditions	0.2	0.2	0.2	0.2	0.3	0.3	0.4	0.5	0.5	0.4	0.5	0.7	1.0	0.5	0.5	0.4	0.4	0.5
Treatment_breathing_machines	0.3	0.3	0.3	0.4	0.4	0.3	0.4	0.4	0.4	0.4	0.4	0.5	0.5	1.0	0.9	0.7	0.6	0.8
Treatment_artificial_nutrition	0.3	0.3	0.3	0.4	0.4	0.3	0.4	0.5	0.4	0.4	0.4	0.5	0.5	0.9	1.0	0.7	0.6	0.8
Treatment_blood_transfusions	0.3	0.3	0.3	0.4	0.4	0.2	0.3	0.4	0.4	0.4	0.4	0.4	0.4	0.7	0.7	1.0	0.8	0.7
Treatment_antibiotics	0.3	0.3	0.3	0.4	0.3	0.2	0.3	0.4	0.4	0.4	0.4	0.4	0.4	0.6	0.6	0.8	1.0	0.7
Treatment_cardiopulmonary	0.3	0.3	0.3	0.4	0.4	0.3	0.4	0.4	0.4	0.4	0.4	0.5	0.5	0.8	0.8	0.7	0.7	1.0

Fig 2. Heatplot of the S-EOL-HLS items, adults aged 50+, SHARE Switzerland, 2019/2020, n = 1,270.

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Kaiser-Meyer-Olkin (KMO) of 0.92 and a statistically significant Bartlett's test of sphericity (chi square = X2 = 7578.036, df = 153, p-value = 0.000). The initial analysis resulted in a three-factor solution; S2 Fig shows two eigenvalues superior to one, one eigenvalue close to one, and all three within the sharp descent [48]. Table 2 outlines the results of the exploratory factor analysis with Promax rotation. The first factor (functional end-of-life health literacy) included six items that explained 34% of the variance and had rotated factor loadings ranging from 0.66 to 0.87. The second factor (interactive end-of-life health literacy) had seven items that explained 32% of the variance, with rotated factor loadings ranging from 0.48 to 0.80. Finally, the third factor (critical end-of-life health literacy) combined five items that described 35% of the variance and had rotated factor loadings between 0.82 to 0.87. Then, the confirmatory factor analysis validated the three-factor model with acceptable fit properties (CFI = 0.993, TLI = 0.992, RMSEA = 0.083, SRMR = 0.061).

To evaluate the construct validity of the S-EOL-HLS, we compared it to the HLS-EU-Q16. Table 3 shows that the partial associations between the two scales and respondents' sociodemographic characteristics were similar. Women were more likely to have both higher end-of-life health literacy and health literacy scores than men. Also, respondents with a middle or high level of education were more likely to have both higher end-of-life health literacy and health literacy scores. Regarding their financial situation, respondents who stated that they have difficulties making ends meet were less likely than those without difficulties to have high

Table 2. Results of exploratory factor analysis with Promax rotation, adults aged 50+, SHARE Switzerland, 2019/2020, n = 635.

	F1	F2	F3
Functional end-of-life health literacy			
Understanding specialized vocabulary—prognosis	0.72		
Understanding specialized vocabulary—intubation	0.75		
Understanding specialized vocabulary—palliative care	0.87		
Understanding specialized vocabulary—cardiopulmonary resuscitation	0.83		
Understanding specialized vocabulary—artificial nutrition	0.78		
Understanding specialized vocabulary—sedation	0.66		
Interactive end-of-life health literacy			
Feel comfortable—defining overtreatment		0.48	
Feel comfortable—talking about end-of-life preferences		0.77	
Feel comfortable—talking about end-of-life treatments		0.80	
Feel comfortable—finding advance directive forms		0.52	
Feel comfortable—making decisions based on probabilities		0.70	
Feel comfortable—choosing treatment type if terminal disease		0.71	
Feel comfortable—defining conditions when to be left to die		0.71	
Critical end-of-life health literacy			
Treatment preference regarding breathing machines			0.82
Treatment preference regarding artificial nutrition			0.84
Treatment preference regarding blood transfusions			0.87
Treatment preference regarding antibiotics			0.82
Treatment preference regarding cardiopulmonary resuscitation			0.82

Rotated factor loadings for each component of the S-EOL-HLS.

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scores on both literacy scales. Finally, compared to respondents who self-reported bad health, those who reported good or excellent health were more likely to have higher end-of-life health literacy and health literacy scores. The two partial associations between the scales that differed were living area and age group: respondents living in a rural area compared to an urban one and those aged 75 years and older compared to younger age group were more likely to have a lower score of end-of-life health literacy; the association was not statistically significant for the health literacy measure.

In addition, Fig 3 presents the respective average scores from the HLS-EU-Q16 and the S-EOL-HLS by categories of end-of-life care planning outcomes. Respondents who had discussed end-of-life wishes issued advance directives, or appointed a surrogate had systematically higher end-of-life health literacy and health literacy scores. However, the differences in average scores were statistically significant only for the S-EOL-HLS.

The results from the ROC analysis comparing the performance of the HLS-EU-Q16 and the S-EOL-HLS on the three end-of-life care planning outcomes are presented in Fig 4. The areas under the curve from the S-EOL-HLS were higher for all three end-of-life planning outcomes. In addition, the score from S-EOL-HLS seemed to be better distributed along the curve, which indicates a better performance.

Discussion

Aging populations with more complex health conditions value health literacy and end-of-life health literacy as important public health issues [49, 50]. Recognizing individuals with limited

Table 3. Partial associations of health literacy and subjective end-of-life health literacy percentage scores with respondents' sociodemographic characteristics, adults aged 50+, SHARE Switzerland, 2019/2020, n = 1,270.

	HLS-EU-Q16	S-EOL-HLS
Gender (male)		
female	4.16***	7.47***
	(0.95)	(1.29)
Age group (58–64 years)		
65–74 years	0.12	-1.77
	(1.15)	(1.59)
75+ years	-1.30	-4.30*
	(1.36)	(1.89)
Education (low)		
middle	3.44*	10.47***
	(1.56)	(2.23)
high	7.06***	16.62***
	(1.67)	(2.46)
Partnership status (has a partner)		
no partner	0.36	-0.64
	(1.25)	(1.72)
Make ends meet (easily)		
fairly easily	-1.01	-1.01
	(1.09)	(1.57)
with difficulty	-6.46***	-7.45**
	(1.94)	(2.68)
Language (German (ch))		
French (ch)	1.01	2.20
	(1.22)	(1.72)
Italian (ch)	-4.12	-7.13
	(3.36)	(5.24)
Living area (urban)		
rural	-1.08	-4.07**
	(0.97)	(1.37)
Self-rated health (bad health)		
good health	8.58***	4.94*
	(1.74)	(2.22)
very good/excellent health	11.85***	11.58***
	(1.73)	(2.18)
Constant	71.90***	58.91***
	(2.65)	(3.41)
Observations	1270	1270

Note, this table shows two Ordinary Least Squares (OLS) regressions of the European Health Literacy Scale (HLS-EU-Q16) percentage score and the Subjective End-Of-Life Health Literacy (S-EOL-HLS) percentage score on the covariates. The table shows the estimates and standard errors in brackets with significance level

* $p < 0.05$,

** $p < 0.01$,

*** $p < 0.001$.

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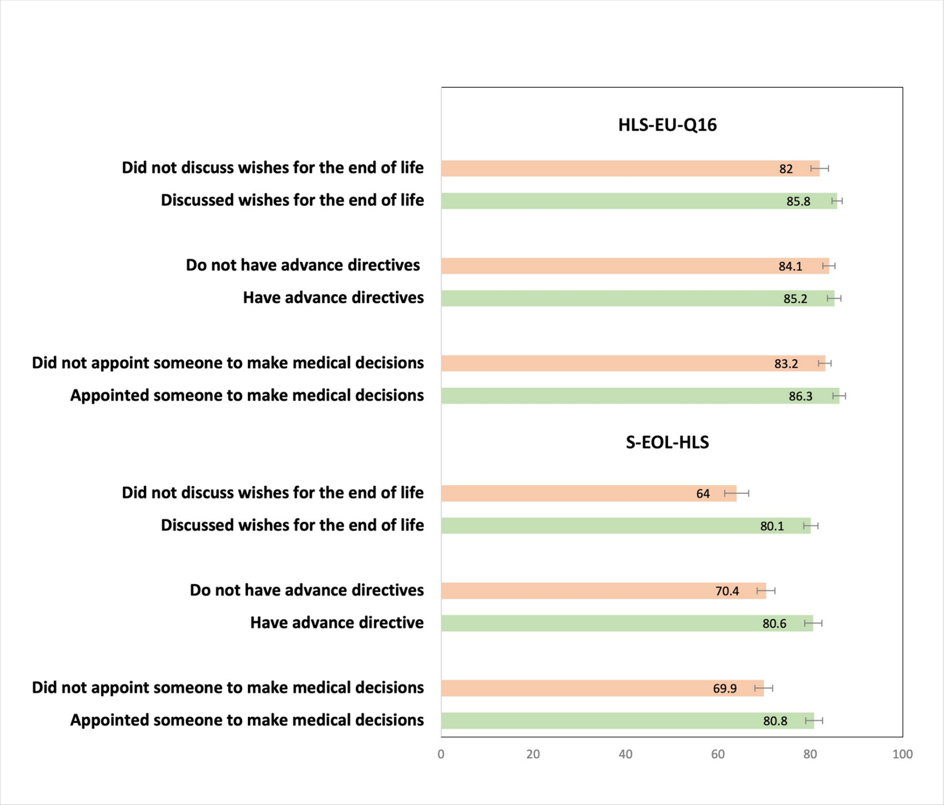

Fig 3. Comparison of the HLS-EU-Q16 and the S-EOL-HLS percentage scores on end-of-life health outcomes, adults aged 50+, SHARE Switzerland, 2019/2020, n = 1,270.

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end-of-life health literacy and enhancing their skills to navigate specific end-of-life healthcare challenges has the potential to bolster their communication and care decision-making capacities. This study is, to the best of our understanding, pioneering in the field of end-of-life health literacy, introducing the first instrument specifically designed and validated to assess individuals' self-perceived abilities to manage end-of-life medical situations. The S-EOL-HLS allows us to draw a comprehensive picture of subjective end-of-life health literacy by measuring individuals' levels of functional, interactive, and critical end-of-life health literacy. The exploratory and confirmatory factor analysis showed that all the fit indices obtained for our samples are within acceptable limits [51]. The reliable and consistent results from the statistical validation thus showed that the S-EOL-HLS is a reliable and valid instrument to measure the end-of-life health literacy of older adults.

The S-EOL-HLS is constructed to ensure comparability with a widely established and validated general health literacy scale (HLS-EU-Q16) [35–37]. When we compared the

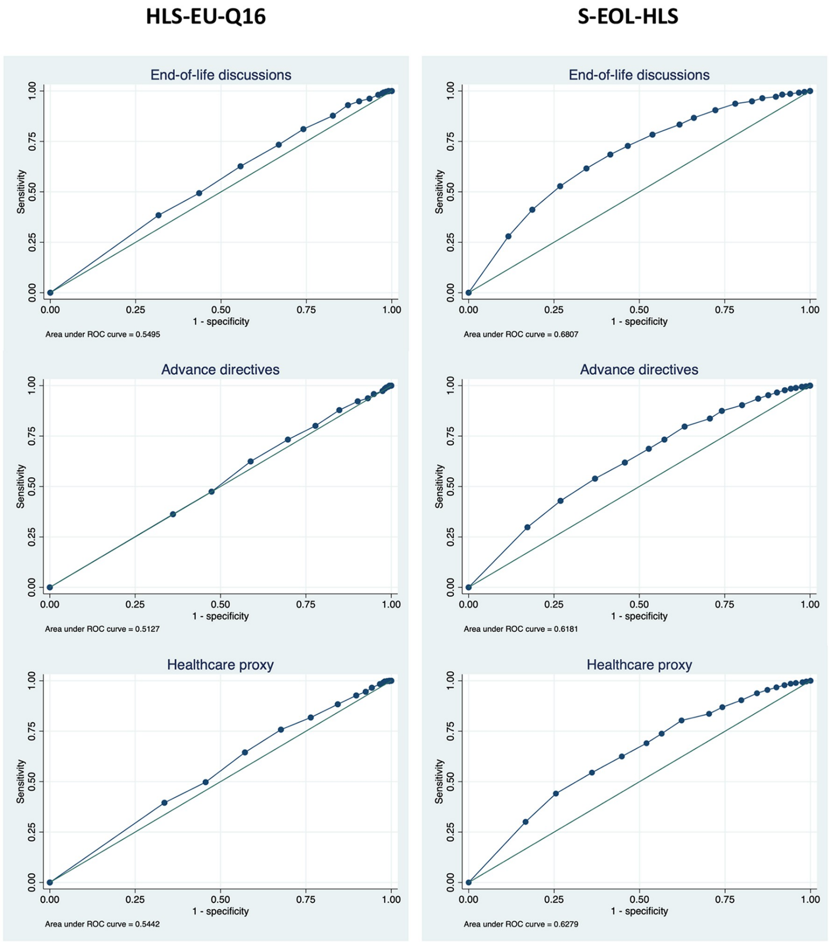

Fig 4. Comparison of the HLS-EU-Q16 and the S-EOL-HLS on end-of-life health outcomes, ROC analysis, adults aged 50+, SHARE Switzerland, 2019/2020, n = 1270.

https://doi.org/10.1371/journal.pone.0292367.g004

discriminant ability of the two scales with regard to social, regional, and health characteristics, we found similar partial associations. These results show that our scale has a sensitivity equivalent to the HLS-EU-Q16 in identifying differences in health literacy levels between social groups. Respondents with a lower end-of-life health literacy score were significantly less likely to have engaged in end-of-life planning behavior. Conversely, individuals who had already engaged in end-of-life care planning found it easier to position themselves on end-of-life care issues. These findings show that the S-EOL-HLS performs better than the HLS-EU-Q16 in detecting individuals who have already engaged in end-of-life care planning for themselves, demonstrating that the goal of the scale is being met. The equal performance of the S-EOL-HLS on detecting social groups with better health literacy than the HLS-EU-Q16 is an additional element to the statistical/metric validation of our scale that indicates that our scale is a reliable and stable measure of end-of-life health literacy. The S-EOL-HLS thus could help to evaluate the level of competencies of older adults to deal with end-of-life care situations.

Differences in responses to the S-EOL-HLS can emerge based on respondents' social backgrounds, geographical locations, and health conditions. For instance, applying the S-EOL-HLS among relatively healthy older adults aged 50+ living in Switzerland can illuminate their perceptions and misconceptions about end-of-life care. This information is valuable in designing proactive guidance and early interventions to enhance end-of-life literacy, facilitating greater preparedness when facing end-of-life decisions. Using the S-EOL-HLS across different population sub-groups may lead to varying results, but each result set offers equally valuable insights.

In terms of practical implications, the S-EOL-HLS could be embedded within larger surveys or administered as a standalone measure, helping to identify segments of the population with sub-optimal end-of-life health literacy. The resulting data can be used to formulate targeted educational strategies and interventions aimed at enhancing their understanding of, and engagement with, end-of-life care and decision-making. Furthermore, the S-EOL-HLS could serve as a valuable instrument in evaluating the effectiveness of interventions that target end-of-life health literacy. By gauging an individual's end-of-life health literacy before and after an intervention, we can quantitatively assess the intervention's success and guide subsequent refinements to enhance its impact. As such, the S-EOL-HLS represents a promising tool for both evaluating and improving end-of-life health literacy, acting as a potential catalyst for more informed and engaged decision-making around end-of-life care.

Further research could use this instrument to test whether individuals with lower end-of-life health literacy are more at risk of being disadvantaged in their quest for goal-concordant care at the end of life. With goal-concordant care being end-of-life care that aligns with an individual's values, preferences, and goals. Individuals with low end-of-life health literacy might have more difficulties understanding key concepts of end-of-life medicine, stating their preferences for end-of-life care, making informed medical decisions, and communicating them, which may prevent them from receiving end-of-life care and treatments in conformity with their wishes. The result could be overtreatment, undertreatment, or inappropriate treatment. Establishing someone's quest for goal-concordant care could be interpreted as individuals' active steps towards ensuring their care aligns with their goals. These steps may involve discussions with healthcare providers, completion of advance care planning documents, or conveying their wishes to family members. Therefore, in conjunction with the S-EOL-HLS assessment, complementary methods could include interviews or surveys involving patients and their family members, or reviewing medical records to identify documented discussions about care goals and corresponding treatment decisions.

The S-EOL-HLS tool could also help assess the impact of interventions aimed at improving end-of-life health literacy. This process would involve the identification of specific strategies, educational programs, or communication initiatives designed to bolster end-of-life health literacy and to measure individuals' end-of-life health literacy pre- and post-intervention studies to assess the effectiveness of such strategies. As individuals become more proficient in understanding, discussing, and making decisions about end-of-life care, they may also become more successful in articulating and pursuing their care goals. This could potentially lead to a higher prevalence of goal-concordant care and help healthcare providers and families to make decisions that better align with the patient's wishes. Evaluating the relationship between improved end-of-life health literacy and the realization of goal-concordant care could yield crucial insights into how best to support individuals during the end-of-life decision-making process.

Additionally, understanding the dynamic nature of end-of-life health literacy presents another potential research area. The S-EOL-HLS could be employed longitudinally to monitor how an individual's end-of-life health literacy evolves over time, particularly in response to significant life events such as receiving a serious illness diagnosis for oneself or a loved one. Such research could uncover trends or patterns in the evolution of end-of-life health literacy, which could in turn inform the development of interventions. Furthermore, understanding how changes in end-of-life health literacy impact the pursuit of goal-concordant care could elucidate the longitudinal relationship between these two constructs, thereby helping to identify optimal moments to support individuals in their quest for end-of-life care that aligns with their preferences.

Finally, while the S-EOL-HLS was designed to test the literacy level regarding one's own health care at the end of life, it could also be useful to develop a tool that measures the literacy to make surrogate end-of-life decisions on behalf of others, commonly family members. In fact, while everyone will only be confronted once in a life with end-of-life decisions regarding oneself, we are usually called multiple times in life to make surrogate end-of-life decisions for others.

Limitations

Our study may have several limitations. First, as a subjective measure, the S-EOL-HLS questionnaire could include reporting bias from respondents who under- or overestimate their actual skills. Nevertheless, subjective health literacy assessments are the most suitable for population surveys for practical reasons. In addition, we know that in some areas, subjective self-assessment is reliable; for instance, self-rated health status predicts mortality very accurately [52]. Finally, in the context of end-of-life decision-making and planning, an individual's perception of their own competence in understanding, discussing, and making informed decisions about end-of-life care can significantly influence their motivation to engage in these important activities. Subjective measures of health literacy have been shown to be positively correlated with self-efficacy [33], which is associated with healthy behavior and better health status [32, 53, 54]. Thus, we assume that individuals who feel competent will be able to engage in end-of-life care planning, in our case, where they will be accompanied and guided by trained professionals who can rectify any remaining misconceptions about end-of-life care situations.

Second, the items of the S-EOL-HLS constitute only a selection of end-of-life literacy skills, which may be incomplete or biased or have limited clinical applicability. Third, the item grouping and question formats from the S-EOL-HLS may have increased the items' correlations within each factor. However, such a design was necessary for administrating questions in an understandable and consistent manner in a self-administered paper-and-pencil questionnaire to a population of older adults. Forth, selection effects and attrition of the SHARE sample might result in representativeness issues of very old adults or individuals with bad health conditions. However, these issues are common to all longitudinal population studies, and considerable efforts are undertaken to minimize these biases in the SHARE survey. Furthermore, the response rate to the Swiss paper-and-pencil questionnaire was very high, and respondents excluded from our analytical sample did not present unexpected characteristics. Finally, it was not possible to validate the scale in the three Swiss national languages separately due to notably the low number of Italian-speaking respondents. However, preliminary analysis showed high internal consistency of the German and French versions of the questionnaire, with Cronbach's alpha of 0.92 for the German subsample and 0.94 for the French.

Conclusion

End-of-life health literacy has become an important public health issue with the aging populations and their ensuing transformation of the last phase of life. Limited end-of-life health literacy presents an additional and substantial barrier to communication and decision-making at the end of life. In addition, Individuals more often have to make complex end-of-life medical decisions in situations of physical and mental impairment—for themselves and others. Improving individuals' abilities and proficiency to deal with situations specific to end-of-life care and medicine would empower them to initiate reflection, communication, and engagement in end-of-life care planning and decisions. This study demonstrated that the S-EOL-HLS is a reliable and valid instrument to measure older adults' self-perceived end-of-life health literacy. The S-EOL-HLS evaluates the level of comfort and competence of the general population in handling end-of-life care situations, its associations with end-of-life care planning outcomes, and its similarities with the results of the HLS-EU-Q16 support this. Future research with the S-EOL-HLS may reveal important insights. It could explore if lower S-EOL-HLS scores correlate with less alignment between patients' preferences and their received end-of-life care. The tool could also assess the impact of interventions aimed at enhancing end-of-life health literacy, offering key evaluation metrics for these initiatives. Additionally, employing the S-EOL-HLS in longitudinal studies may help elucidate how end-of-life health literacy evolves in response to major life events, such as personal or family illness diagnoses.

Supporting information

S1 Fig. The 3-factors model of the S-EOL-HLS.
(TIF)

S2 Fig. S-EOL-HLS scree plot of eigenvalues.
(TIF)

S1 Table. The 18 items from the S-EOL-HLS scale.
(DOCX)

S2 Table. The 16 items from the HLS-EU-Q16 scale.
(DOCX)

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4.5 Article V

Title: End-of-life health literacy, knowledge, and attitudes toward advance care planning among older adults in Switzerland

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End-of-life health literacy, knowledge, and attitudes toward advance care planning among older adults: cross-sectional evidence from Switzerland

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Keywords

End-of-life health literacy; knowledge; advance care planning; population-based study; older adults; Switzerland; Survey of Health, Ageing, and Retirement in Europe (SHARE)

Abstract

Introduction:

Population aging, technological advancements, and an increasing emphasis on patient empowerment imply that individuals are increasingly confronted with intricate end-of-life decisions. Personal end-of-life health literacy skills may help empower individuals to participate more actively in their own end-of-life decisions, including engagement in advance care planning (ACP). This study thus investigates the associations between individuals' end-of-life health literacy and their knowledge and attitudes toward ACP among a population-based sample of adults aged 58+ in Switzerland.

Method:

We used data from 1,319 respondents from Wave 8 (2019/2020) of the Survey on Health, Ageing, and Retirement in Europe. Subjective end-of-life health literacy was measured using the S-EOL-HLS scale. Respondents' end-of-life knowledge was assessed using test-based questions about 11 end-of-life medical situations. Attitudes toward ACP were measured by whether respondents have discussed their end-of-life wishes, completed advance directives (AD), and appointed a potential surrogate for medical decisions in case of incapacity. Associations were estimated using separate ordinary least square and probit regressions, controlling for social, health, and regional characteristics.

Results:

Respondents with higher end-of-life health literacy tended to have better end-of-life knowledge and were more likely to have discussed their end-of-life wishes, to have completed AD, and to have appointed a surrogate for medical decisions in case of incapacity. Upon regressing the outcomes on the three end-of-life health literacy dimensions, interactive health literacy positively correlated with end-of-life knowledge and the three attitudes toward ACP, while critical health literacy was only associated with having an AD and appointing a surrogate for medical decisions.

Conclusions:

Our findings suggest that end-of-life health literacy may play a significant role in individuals' level of end-of-life knowledge and their attitude toward ACP. Thus, developing public health policies aimed at strengthening their end-of-life health literacy skills may increase individuals' engagement in the ACP process and make ACP more effective.

Key Messages

- Individuals' health literacy significantly impacts their attitudes toward ACP, yet existing research relies on general health literacy measures; thus, this study employs the Subjective End-of-life Health Literacy Scale to comprehensively assess the relationship between end-of-life health literacy and ACP attitudes in older Swiss adults.

- This study reinforced that higher end-of-life health literacy is correlated with better end-of-life knowledge and positive attitudes toward ACP. Those with higher end-of-life health literacy are more likely to discuss end-of-life preferences, complete AD, and appoint a medical surrogate. Among three end-of-life health literacy dimensions, the interactive dimension—focused on effective communication and engagement—stands out as the most influential.

- The findings underscore the need for interventions that provide tailored information and support to older adults in engaging in ACP. Solutions such as specific consultations with healthcare professionals, a national day focusing on end-of-life discussions, or the introduction of a "Personal Healthcare Guide" can help improve individuals' end-of-life health literacy. Future research should explore the impacts of different demographics on end-of-life literacy and work on developing objective measures for a more comprehensive understanding. The results lay a foundation for strategies that prioritize the needs of older adults, facilitating a more dignified and respectful end-of-life process.

Words count: 4,374.

Introduction

Over recent decades, the need to make important end-of-life healthcare decisions has increased drastically [1]. This growth can be attributed to medical advancements that extend life, potential concerns about overtreatment, and an evolving relationship between patients and healthcare providers, which now emphasizes patient autonomy and self-determination in medical decisions [2,3]. Furthermore, end-of-life decisions present their own set of challenges, often asking individuals to contemplate future hypothetical scenarios or confront current situations burdened with emotionally charged decisions. The complexity of end-of-life decisions arises from the acuity of the situation, the multitude of options available, uncertainties particularly concerning prognosis, a common lack of preparation, and often impaired decisional capacity, whereby relevant scenarios frequently require individuals to weigh the trade-offs between quality and quantity of life [4,5]. As a result, individuals may have to make challenging decisions about situations that are highly uncertain and about which they often have very little knowledge [6,7].

Advance care planning (ACP) is a proactive approach involving structured discussions between healthcare professionals, (potential) patients, and often their families, anticipating possible health deterioration leading to decisional incapacity [8]. Its primary objective is to align medical treatments with patients’ preferences, thereby promoting their quality of life throughout their healthcare journey and leading to better end-of-life experiences as perceived by the patient [9–11]. This process often culminates in the drafting of an advance directive (AD), i.e., documented decisions that encapsulate patients’ medical preferences, particularly regarding treatments they would have to accept or decline in situations where they may have become incapacitated, and information regarding the person they designated to make medical decisions for them in case of incapacity [12]. These processes and documents can play a pivotal role in protecting patient autonomy, ensuring that medical interventions resonate with their personal wishes, and offering guidance to families and healthcare practitioners in challenging decision-making situations [13]. Despite the potential benefits of ACP, such as enhanced patient satisfaction, greater respect for patient autonomy, and care more in line with patients' wishes [14–16], there remains a noticeable lack of awareness and engagement in ACP and AD use among the general population [17–19]. This gap is especially pronounced among vulnerable older adults and those with limited health literacy [20].

Individuals’ attitudes toward ACP often appear to be shaped by their health literacy, which has been shown to affect their understanding of health challenges, their communication with medical professionals, and their ability to make informed medical decisions [21,22]. Specifically, prior research showed that limited health literacy had been associated with suboptimal self-care behavior for diabetes [23], poor health-related knowledge of chronic diseases [24], communication gaps between patients and healthcare providers when discussing end-of-life care [25], misunderstandings about end-of-life treatment options [26], an increased probability of undergoing aggressive end-of-life care [27], lesser engagement in ACP [28,29], and fewer chances of having an AD [30]. Moreover, health literacy has emerged as a pivotal factor in determining ACP engagement [31,32]. While associations between health literacy and knowledge regarding ACP have been documented in existing literature [33], much of the existing research has relied upon rather general health literacy measures such as the Test of Functional Health Literacy in Adults (TOFHLA) [34]. These broad measures may often fail to capture important nuances related to end-of-life decisions, especially in emotionally charged situations of life and death, the heightened role of uncertainty, and potential trade-offs between length and quality of life. Such decisions demand a deeper comprehension, given their sensitive nature. To fill this gap, the present study uses the recently validated Subjective End-of-life Health Literacy Scale (S-EOL-HLS) [35] to investigate the associations between individuals' end-of-life health literacy and their knowledge and attitudes toward ACP among a population-based sample of adults aged 58+ in Switzerland. Another distinctive feature of this research is its use of the three dimensions within the S-EOL-HLS: functional, interactive, and critical end-of-life health literacy. Designed to provide a multifaceted perspective on end-of-life health literacy, these dimensions allow our study to shed more light on the intricate associations between end-of-life health literacy and ACP, offering a comprehensive perspective absent in prior research on general health literacy and ACP.

Materials and methods

Study design and participants

We used cross-sectional data from the 8th Wave of the Survey on Health, Ageing, and Retirement in Europe (SHARE) that was collected between October 2019 and the beginning of March 2020 [36,37]. SHARE collects data every two years from targeted respondents and their partners aged 50 years and older in 28 European countries and Israel using Computer-Assisted Personal Interviewing. The internationally harmonized, questionnaire-based in-person interview collects information on individuals' health, socioeconomic status, and social networks. In addition, each country can add a country-specific paper-and-pencil self-administrated questionnaire. Our analyses include respondents from Switzerland who participated in the main questionnaire and the national paper-and-pencil questionnaire from Wave 8 on end-of-life issues. The Swiss study obtained ethical approval number 66/14 from the ethics committee of the canton of Vaud in March 2014. Respondents consented to participate twice, when they agreed to schedule an interview, and when they attended the in-person interview. SHARE samples are designed to be nationally representative of the target population of adults aged 50 years and older. However, as the Swiss sample has not been refreshed since 2011, we only include respondents aged 58 and older in our analysis. In Switzerland, 2,009 respondents participated in the main SHARE questionnaire; 94.4% also answered the national paper-and-pencil questionnaire (n=1,896). After excluding respondents' partners aged 50-57 years and those with missing responses on variables used in the analysis, our final analytical sample includes 1,319 respondents.

Outcome variable

End-of-life knowledge. The Swiss paper-and-pencil questionnaire integrated 11 items on the likelihood of important potential end-of-life medical situations that the respondents had to evaluate on a 4-point scale: 1 = very unlikely (0–25%), 2 = rather unlikely (26%–50%), 3 = rather likely (51%–75%), and 4 = very likely (76%–100%). The end-of-life medical situations referred to issues like cognitive impairment, medical treatment, and place of death (see Appendix 2). Following the approach of a previous study that used the same set of end-of-life knowledge questions [6], we defined the accuracy of perceptions of different end-of-life situations using dichotomized variables: 1 indicates a correct answer, and 0 indicates an incorrect answer. The resulting initial end-of-life knowledge score that summed up all correct answers ranged from 0 to 9, as no respondents answered all questions correctly. Following the approach from Pelikan et al. (2019) [38], missing values were treated as 0, and the final end-of-life knowledge score only includes respondents with no more than two missing values on the items. In total, 259 respondents (15.1%) had more than two missing values on the 11 items. The score was then standardized by dividing it by its standard deviation (1.78) and finally ranged from 0 to 5.1. This standardization was done to normalize the distribution and make the score more interpretable in the context of our analysis.

Attitudes toward ACP. Respondents were asked whether they had ever discussed their wishes for the end of their life with someone (0= no, 1= yes), whether they had completed a written statement about their wishes and refusals for medical treatments and care (AD/living will) (0= no, 1= yes) and whether they had appointed someone in writing to make medical decisions for them should they not be able to make those decisions for themselves (durable power of attorney, 0= no, 1= yes).

Exposure

Subjective End-of-life Health Literacy Scale (S-EOL-HLS). The Swiss paper-and-pencil questionnaire included the items from the S-EOL-HLS [35]. The scale measures individuals' subjective assessment of their end-of-life health literacy skills, in particular regarding end-of-life decision-making. The instrument consists of 18 items (see Appendix 1) divided into three dimensions (1) functional end-of-life health literacy, where respondents have to rate their level of understanding end-of-life medical terms, (2) interactive end-of-life health literacy, which assesses respondents' self-rated ease in defining treatment goals, in finding information on end-of-life planning options and in communicating about end-of-life issues; and (3) critical end-of-life health literacy, which asks respondents to indicate their self-rated competency in choosing medical treatments. Respondents evaluate each item on a 4-point Likert scale with answers ranging from "very easy," "fairly easy," "fairly difficult," to "very difficult." The items are then dichotomized with a value of "0" for "very difficult" and "fairly difficult" and a value of "1" for the categories "very easy" and "fairly easy," allowing us to construct a score from 0 to 18. Following the approach from Pelikan et al. (2019) [38], missing values were treated as 0, and the final end-of-life health literacy score was then computed for respondents with no more than two missing item values. In total, 116 respondents (6.8%) had more than two missing values on the 18 items. The score was then standardized by dividing it by its standard deviation (4.6), resulting in a range from 0 to 3.9. To deepen the analysis, three standardized end-of-life health literacy subscores were calculated based on the three dimensions of the scale: functional, interactive, and critical end-of-life health literacy.

Covariates

Our statistical models include information on sex (male, female), age (58-64 years, 65-74 years, 75+ years), education levels (low= International Standard Classification of Education (ISCED) levels 0-1-2, middle= ISCED levels 3-4, high= ISCED levels 5-6 [39]), partnership status (has a partner, has no partner), Switzerland's linguistic regions (German, French, or Italian), subjective financial difficulties (ability to make ends meet: easily, fairly easily, and with difficulty), living area (urban, rural), self-rated health (poor/fair health, good health, very good/excellent health).

Statistical analysis

The characteristics of the study population were described using number counts and proportions. A binned scatterplot assessed the bivariate association between standardized end-of-life health literacy and end-of-life knowledge scores. Bivariate associations between average standardized end-of-life health literacy score and attitudes toward end-of-life healthcare planning were computed with bar charts. The partial association between the standardized end-of-life health literacy score and the standardized end-of-life knowledge score was assessed using ordinary least square regressions, while the respective associations between the standardized end-of-life health literacy score and the three attitudes toward ACP were explored using separate probit regression models. The same statistical modeling was used when considering the three dimensions of the end-of-life health literacy scale as exposures. Each regression model controlled for sex, age, education levels, partnership status, Switzerland's linguistic regions, subjective financial difficulties, living area, and self-rated health. In addition, to account for potential unobserved dependencies between the target respondents and their patterners, the error terms were clustered at the household level. All estimations used STATA/SE 17.0 software (STATA

Corporation, College Station, TX), and results were reported as average marginal effects (AME) along with corresponding standard errors (SE) clustered at the household level.

Results

Selected characteristics of the study participants are displayed in Table 1. Overall, 51.5% of the participants were female, and the mean age was 70.6 years old (SD: 7.9), respondents were distributed across three age groups: 26.7% were between 58-64 years, 43.9% were between 65-74 years, and 29.4% were 75 years or older. Concerning education, 64.3% had a middle education level, 21.1% had a high education level, and 14.6% had a low education level. Regarding partnership status, 77.4% had a partner. Financially, 56.5% found it "easy" and 31.5% "fairly easy" to make ends meet at the end of the month. Regarding the language region of Switzerland, 72.8% resided in the German-speaking parts, 24% in the French-speaking parts, and 3.2% in the Italian-speaking parts. Geographically, 45% lived in urban settings and 55% in rural areas. As for health assessment, 41.6% rated their health as good and 42.2% as very good or excellent. Concerning end-of-life healthcare planning, 66.6% had discussed their end-of-life wishes, 42.5% had completed AD, and 44.4% had appointed a surrogate to decide on medical matters.

[Insert Table 1 here]

The bivariate associations displayed in Figure 1 describe the relationship between the standardized end-of-life health literacy score and both the standardized end-of-life knowledge score and attitudes toward ACP. The scatterplot graph demonstrates a positive association between end-of-life health literacy and knowledge; a higher standardized end-of-life health literacy score is associated with a higher standardized end-of-life knowledge score. As for the subsequent three bar charts, respondents who had discussed their end-of-life wishes, completed an AD, or appointed a surrogate for medical decisions consistently exhibited higher standardized end-of-life health literacy scores.

[Insert Figure 1 here]

Table 2 shows the partial associations between the standardized end-of-life health literacy scores, the standardized end-of-life knowledge score and attitudes toward ACP. A one standard deviation higher end-of-life health literacy score is associated with an increase in the standardized end-of-life knowledge score (AME: 0.17, $p < 0.001$), the likelihood of discussing end-of-life preferences (AME: 0.14, $p < 0.001$), the completion of AD (AME: 0.13, $p < 0.001$), and the appointment of a medical decision surrogate (AME: 0.12, $p < 0.001$). These findings have been adjusted for several covariates, including sex, age, education levels, partnership status, subjective financial situation, linguistic region, living area, and self-assessed health.

[Insert Table 2 here]

The partial associations between the standardized end-of-life knowledge score, attitudes toward ACP and the three standardized scores of the distinct dimensions of end-of-life health literacy are presented in Table 3. The interactive dimension of end-of-life health literacy demonstrates the most consistent positive association with the exposure variables. An increase in the interactive end-of-life health literacy score correlates with an increased standardized end-of-life knowledge score (AME: 0.17, $p < 0.001$), a higher likelihood of engaging in end-of-life discussions (AME: 0.12, $p < 0.001$), completion of AD (AME: 0.10, $p < 0.001$), and designation of a surrogate for medical decisions (AME: 0.08, $p < 0.001$). The critical dimension also exhibits associations, notably with the completion of AD (AME: 0.04, $p < 0.05$) and the appointment of a surrogate (AME: 0.06, $p < 0.001$). However, the associations related to the functional dimension are not statistically significant. All these associations have been adjusted for the same covariates as in Table 2.

[Insert Table 3 here]

Discussion

Using data of 1,319 adults aged 58 and older from Switzerland, this study explored the relationships between end-of-life health literacy, knowledge, and attitudes toward ACP. A positive correlation emerged, indicating that individuals with higher standardized end-of-life health literacy scores tend to possess better knowledge about end-of-life medical situations and are more proactive in planning for it. Particularly, the results highlight the association between increased end-of-life health literacy and the likelihood of discussing end-of-life preferences, completing AD, and appointing a surrogate for medical decisions. Among the three dimensions of end-of-life health literacy assessed, the interactive dimension emerged as the most associated with the four outcomes' variables. On the other hand, while the critical dimension also presented some notable associations, the functional dimension showed a clear tendency for better end-of-life knowledge and more positive attitudes toward ACP, but the corresponding associations did not turn out to be statistically significant. The findings from this study reinforce and complement previous research that has demonstrated the importance of health literacy in influencing various attitudes toward ACP. However, what sets this research apart is its in-depth exploration of some aspects of the ACP process using a nuanced measure of end-of-life health literacy.

End-of-life knowledge and attitudes toward ACP

One significant obstacle to the wider adoption of AD and active engagement in ACP is a lack of knowledge to navigate the intricate landscape of end-of-life medical decisions [33]. However, so far, only a few studies have focused on the general population and their understanding of end-of-life healthcare options. Studies conducted in North America using knowledge assessment tests consistently indicate a significant knowledge gap concerning end-of-life care options among the general public [40–42]. Another study found that while most older adults in China value healthcare transparency and autonomy, there is a significant lack of awareness and preference for ACP, potentially influenced by traditional values and education levels [43]. In addition, a population-based telephone survey in Hong Kong exploring attitudes and preferences of older adults regarding ACP revealed significant gaps between individuals' preferences to communicate and make their own end-of-life decisions and their awareness of ACP, with many also unfamiliar with AD [44]. Moreover, a study in Wales exploring public views on death and end-of-life care revealed the need to address societal taboos around death discussions, especially in light of the increased awareness brought about by the COVID-19 pandemic [45]. Finally, a study on older adults aged 55+ in Switzerland found notable misunderstandings about end-of-life healthcare and planning, potentially leading to suboptimal end-of-life decisions and limited patient participation [46]. Given the clear knowledge gaps highlighted in multiple studies about end-of-life decisions among older adults and considering that improved end-of-life healthcare knowledge enhances participation in ACP [47–51] and the completion of AD [52,53], tackling this lack of awareness is essential.

End-of-life health literacy and its importance for ACP

Addressing knowledge gaps in end-of-life healthcare and related attitudes toward ACP requires focusing on empowering individuals to take control of their end-of-life decisions. As highlighted in a previous study analyzing health literacy and end-of-life healthcare preferences, to support individuals effectively, it is essential to enhance their health literacy, ensuring they are well-informed and possess the necessary skills to make informed health-related decisions [54]. Two other studies supported those results, the first one showing that health literacy strongly influences knowledge, attitude, and decisions about hospice care among older adults [55] and the second one that health literacy significantly influences older adults' understanding of ACP more than their prior experience with ACP [56]. Although previous studies utilized general health literacy measures rather than one tailored specifically to end-of-life situations, they underscored the significance of health literacy skills in end-of-life healthcare decisions. With adequate end-of-life health literacy skills, individuals could improve their understanding of medical terms and the different types of end-of-life healthcare options, reduce their emotional barriers when communicating with healthcare providers and their loved ones, and thus facilitate healthcare that aligns with their preferences [21]. Therefore, as highlighted by the results from our study, individuals' competencies for end-of-life decisions are crucial, as they positively correlate with end-of-life healthcare knowledge, discussions about end-of-life wishes, AD completion, and the designation of a medical decision surrogate. Ultimately, enhancing end-of-life health literacy and increasing the adoption of ACP can foster a dignified and respectful end-of-life process while alleviating the decision-making burden frequently shouldered by family members and healthcare providers.

End-of-life health literacy dimensions

This research shows that end-of-life health literacy is positively associated with individuals' end-of-life knowledge and attitudes toward ACP and identifies specific dimensions of end-of-life health literacy that are crucial for supporting patients, their loved ones, and healthcare providers in their collective aim to align end-of-life healthcare with patients' values, preferences, and goals. Focusing on distinct dimensions of functional, interactive, and critical end-of-life health literacy, provides a deeper understanding than studies that mainly relied on general health literacy measures. The first dimension, functional end-of-life health literacy, measures individuals' comprehension of common end-of-life medical terms [35]. This dimension appeared to be the least influential, as its associations with end-of-life knowledge and attitudes toward ACP were not statistically significant. This suggests that only possessing the basic skills to understand end-of-life medical terms may be insufficient for individuals to have higher end-of-life knowledge and positive attitudes toward ACP. The second dimension, interactive end-of-life health literacy, evaluates respondents' self-assessed challenges in defining treatment goals, obtaining information on end-of-life healthcare planning options, and discussing end-of-life matters [35]. Of all the dimensions, this one showed the most consistent associations with the outcomes of interest. Results indicated that higher scores in interactive end-of-life health literacy correlate with better knowledge of end-of-life, more discussions on the topic, higher completion rates of AD, and more designation of a medical decision surrogate. These findings underscore the significance of the interactive dimension in end-of-life knowledge and attitudes toward ACP. It highlights the need to emphasize advanced cognitive and social skills, enabling individuals to engage in meaningful communication with healthcare providers, actively participate in ACP, and gain a deeper comprehension of the dying process. In addition, it underscores that the more proactive aspects of ACP, such as seeking information and discussing end-of-life issues, can be challenging for some individuals. Therefore, providing them with the opportunity to initiate this process with support can be beneficial in encouraging engagement in ACP. Lastly, the critical end-of-life health literacy dimension estimates respondents' difficulties in choosing end-of-life medical treatments [35]. Results from this dimension showed notable positive associations with both AD completion and surrogate appointment. These results from the critical dimension indicate that advanced cognitive and social skills, crucial for analyzing and utilizing information, are essential for individuals when translating the gathered information and informative discussions into making definitive decisions about end-of-life medical treatments.

Practical implications and future research

Existing research has shown that limited health literacy can lead to suboptimal participation and engagement in ACP [28,29]. This study emphasizes the pivotal role of end-of-life health literacy in this regard. The results suggest the need for new targeted interventions that would not only provide simplified information on end-of-life issues but also support older adults in engaging in the ACP process and strengthening their skills. Such interventions could include offering consultations with health professionals to discuss potential decisions concerning end-of-life medical situations. For instance, in the Netherlands, research showed that inviting older adults to information sessions about end-of-life healthcare led by general practitioners can positively impact individuals' engagement in ACP [57]. The authors further explained that although this approach mainly resonates with older individuals already curious about the topic, it appears to be a straightforward way to encourage ACP [57]. It is also crucial to enlighten healthcare providers about the significance of assessing the health competency level of patients concerning end-of-life healthcare. This would enable them to tailor their communication, fostering better understanding between patients and healthcare providers. In a prospective study conducted in four palliative care units in Switzerland, the authors found that healthcare providers' attitudes might hinder patients from discussing potential future complications or completing AD; suggesting that the approach and perspectives of healthcare providers can significantly impact patient decisions regarding end-of-life healthcare [58]. Moreover, establishing another type of intervention for the public, such as a national day focusing on end-of-life issues, could serve as an excellent platform for widespread discussion, potentially equipping the general population with a deeper understanding of these intricate matters. Furthermore, when considering the significant impact that media coverage of personal ACP experiences has on health decisions [59], integrating such narratives into a national day could significantly enhance end-of-life health literacy among the general population. Finally, within the broader healthcare landscape, introducing a mandatory "Personal Healthcare Guide" for older adults similar to vaccine booklets for children that details end-of-life healthcare options aligned with personal values, preferences, and goals could not only bolster individual end-of-life planning skills but also encourage healthcare providers to initiate crucial end-of-life discussions, guide older adults in maintaining these records, and prompt the healthcare system to prioritize the needs of the aging population.

Future studies might expand the scope of this study and investigate the differential impact of end-of-life health literacy across diverse demographic groups. Given the cultural, socioeconomic, and educational differences, understanding how these groups vary in their end-of-life health literacy can inform targeted interventions. In addition, there is a need for the development and validation of objective measures for end-of-life health literacy, which could offer complementary insights to subjective assessments. Also, while our study emphasized three distinct dimensions of end-of-life health literacy, future research might explore other facets or different breakdowns of these dimensions in the context of end-of-life healthcare. Moreover, as the field of end-of-life healthcare evolves, it is important to constantly investigate significant factors such as end-of-life health literacy determinants in assuring a dignified and respectful end-of-life process for patients, their loved ones, and healthcare providers. Finally, future research should prioritize designing and rigorously evaluating interventions to enhance EOL health literacy, ensuring that new strategies are both effective and evidence-based.

Limitations

Our research acknowledges several limitations. First, despite the extensive use and convenience of subjective measures like the S-EOL-HLS, they may be subject to potential reporting biases. Depending on their familiarity with end-of-life issues, participants might undervalue or overstate their actual skills. Second, the S-EOL-HLS items cover only a subset of the broad spectrum of end-of-life health literacy skills, which can raise questions about the data's comprehensiveness, potential bias, and clinical relevance. Moreover, in measuring end-of-life knowledge, the use of both qualitative and quantitative labels for answer categories might have confused some participants. While some might have relied solely on one type of label when responding, others could have found the probability concepts challenging, even though such questions have been consistently used in the SHARE study. Additionally, while SHARE strives for an accurate representation of Switzerland's older population, potential attrition, a common challenge in longitudinal studies, especially among the oldest and most frail participants, could influence our results. Challenges around sample representation might also suffer from issues such as item nonresponse. However, the high response rate to the Swiss questionnaire and the consistent characteristics of those excluded from our sample offer some reassurance in our findings.

Conclusion

This study on 1,319 older Swiss adults revealed a strong positive correlation between end-of-life health literacy, end-of-life knowledge, and positive attitude toward ACP. Individuals with higher end-of-life health literacy were more likely to discuss end-of-life preferences, complete AD, and appoint a medical surrogate. The interactive dimension of end-of-life health literacy seemed to be the most influential, underscoring the importance of individuals' cognitive and social skills to communicate effectively with healthcare providers about care preferences, engage in advance care planning, and develop a deeper understanding of the process of dying to help them making end-of-life decisions. Despite the importance of advance care planning, barriers such as limited awareness and knowledge gaps hinder its widespread adoption. Enhancing end-of-life health literacy can bridge these gaps, leading to more informed decisions that respect patient autonomy and reduce burdens on families and healthcare providers. The results also highlight the need for targeted interventions such as offering older adults specific ACP consultations with healthcare professionals, improving patient-healthcare provider communication, creating a national end-of-life day, or introducing a "Personal Healthcare Guide" to bolster end-of-life planning and prioritize the needs of older adults. Finally, future research should explore diverse demographic impacts on end-of-life literacy and develop objective measures for more comprehensive insights and improved end-of-life patient healthcare.

Conflict of interest Declaration of Generative AI and AI-assisted technologies in the writing process

During the preparation of this work, the author(s) used OpenAI's ChatGPT and Grammarly in order to assist with the grammatical refinement of the paper. After using these tools/services, the author(s) reviewed and edited the content as needed and take(s) full responsibility for the content of the publication.

Conflict of interest

The authors declare that they have no competing interests.

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Data sharing statement

This paper uses data from Börsch-Supan, A. (2022). Survey of Health, Ageing and Retirement in Europe (SHARE) Wave 8. Release version: 1.0.0. SHARE-ERIC. Data set. DOI: 10.6103/SHARE.w8.100. Study data already de-identified are available to the scientific community upon submitting a data requestion application to the SHARE study.

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Authors contribution

CM, SV, MW, and JM designed the study. CM conducted the analysis and drafted the article. All authors discussed the interpretation of findings and provided critical revision of the article for important intellectual content.

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Table 1: Characteristics of the study population, adults aged 58+, SHARE Switzerland, 2019/2020, n=1,319

	n	%
Gender		
Male	639	48.5
Female	680	51.5
Age groups		
58-64 years	352	26.7
65-74 years	579	43.9
75+ years	388	29.4
Education		
Low	192	14.6
Middle	848	64.3
High	279	21.1
Partnership status		
Has a partner	1,021	77.4
No partner	298	22.6
Make ends meet		
Easily	745	56.5
Fairly easily	416	31.5
With difficulty	158	12
Language		
German	960	72.8
French	316	24
Italian	43	3.2
Living area		
Urban	594	45
Rural	725	55
Self-rated health		
Poor/fair health	214	16.2
Good health	548	41.6
Very good/excellent health	557	42.2
EOL discussions		
No	441	33.4
Yes	878	66.6
Completed AD		
No	759	57.5
Yes	560	42.5
Appointed surrogate		
No	733	55.6
Yes	586	44.4
Standardized EOL health literacy score	mean: 2.9 min: 0	std. dev: 1 max: 3.9
Standardized EOL knowledge score	mean: 1.7 min: 0	std. dev: 1 max: 5.1

Note, number of observations for the whole sample. AD = Advance Directives. EOL = End-Of-Life.

Table 2: Partial associations between EOL knowledge and attitudes toward ACP on the standardized EOL health literacy score, adults aged 58+, SHARE Switzerland, 2019/2020, n=1,319

	EOL knowledge	EOL discussions	Completed AD	Appointed surrogate
Standardized EOL health literacy score	0.17^{***} (0.03)	0.14^{***} (0.01)	0.13^{***} (0.01)	0.12^{***} (0.01)
Observations	1,319	1,319	1,319	1,319

*The table shows average marginal effects and standard errors in parentheses. Statistical significance: * p < 0.05, ** p < 0.01, *** p < 0.001. AD = Advance Directives. EOL = End-Of-Life. ACP = Advance Care Planning. The first column shows the results from an ordinary least squares regression of the standardized EOL knowledge score on the standardized EOL health literacy score and the covariates. The next three columns present probit regressions models regressing each EOL health outcomes on the standardized EOL health literacy score and the covariates. The covariates include sex, age, education levels, partnership status, subjective financial situation, linguistic region, living area and self-rated health.*

Table 3: Partial associations between EOL knowledge and attitudes toward ACP on the three dimensions from the standardized EOL health literacy score, adults aged 58+, SHARE Switzerland, 2019/2020, n=1,319

	EOL knowledge	EOL discussions	Completed AD	Appointed surrogate
Standardized functional EOL health literacy score	0.03 (0.03)	0.02 (0.01)	0.01 (0.02)	0.01 (0.02)
Standardized interactive EOL health literacy score	0.17^{***} (0.04)	0.12^{***} (0.01)	0.10^{***} (0.02)	0.08^{***} (0.02)
Standardized critical EOL health literacy score	0.00 (0.03)	0.02 (0.01)	0.04^{*} (0.02)	0.06^{***} (0.02)
Observations	1,319	1,319	1,319	1,319

*The table shows average marginal effects and standard errors in parentheses. Statistical significance: * p < 0.05, ** p < 0.01, *** p < 0.001. AD = Advance Directives. EOL = End-Of-Life. ACP = Advance Care Planning. The first column shows the results from an ordinary least squares regression of the standardized EOL knowledge score on the three dimensions of the standardized EOL health literacy score and the covariates. The next three columns present probit regressions models regressing each EOL health outcomes on the three dimensions of standardized EOL health literacy score and the covariates. The covariates include sex, age, education levels, partnership status, subjective financial situation, linguistic region, living area and self-rated health.*

Appendices

Appendix 1: the 18 items from the S-EOL-HLS scale:

Question 1: The medical community uses specialized vocabulary. We would like to know whether it is easy or difficult for you to understand what the following medical terms means:

Answer categories: "Very easy", "Fairly easy", "Fairly difficult", "Very difficult"

a) Prognosis
b) Intubation
c) palliative care
d) cardiopulmonary resuscitation
e) artificial nutrition
f) sedation

Question 2: We would like to know how comfortable you feel with the following situations. For you, is it easy or difficult to…

Answer categories: "Very easy", "Fairly easy", "Fairly difficult", "Very difficult"

a) Define what is overtreatment for you?
b) Talk about your end-of-life preferences with someone you trust such as a close family member or friend?
c) Talk to a physician or other medical expert to learn more about advance care planning tools and end-of-life treatments?
d) Find information and/or obtain template forms to complete a so-called “advance directives”?
e) Make decisions on whether to accept a treatment or not based on probabilities regarding chances of different treatment outcomes?
f) Choose between comfort care (relieving suffering without slowing the disease) and aggressive life-prolonging treatment (heavy chemotherapy, intensive care with artificial ventilation) should you suffer from a terminal disease?
g) Define specific conditions or situations in which you would prefer to be left to die?

Question 3: Imagine being asked today to write down whether or not you would like to receive certain medical treatments in a situation in which you are no longer able to decide for yourself (advance directives). How easy or difficult is it for you to indicate today in writing whether you wish to receive or refuse the following treatments at the end of life?

Answer categories: "Very easy", "Fairly easy", "Fairly difficult", "Very difficult"

a) breathing machines
b) artificial nutrition
c) blood transfusions
d) antibiotics
e) cardiopulmonary resuscitation

Appendix 2: End-of-life medical situations questions:

People have representations of end-of-life medical situations. We would like to know yours.

We would like to know whether you think that the situations described below and related to end-of-life are very unlikely (0-25%), rather unlikely (26-50%), rather likely (51-75%), or very likely (76-100%).
If you don't know, please give us your best estimate.

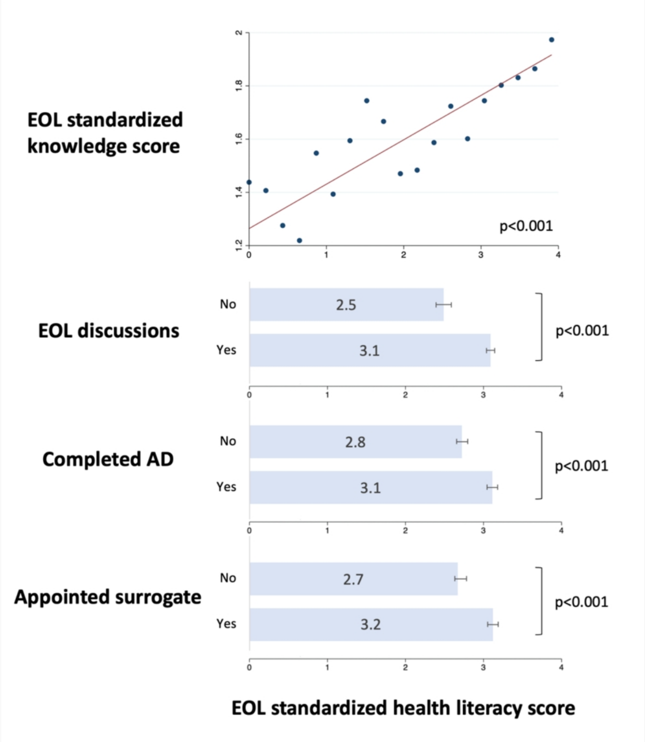
Example: "In your opinion, what are the chances that it is snowing tomorrow?" If you tick "very likely," you consider that the chances that it is snowing tomorrow range between 76% and 100%.

In your opinion, how likely is it **in general in Switzerland…**

Answer categories: "very unlikely (0-25%)", "rather unlikely (26-50%)", "rather likely (51-75%)", "very likely (76-100%)"

1) To suffer from dementia at the age of 75? **(dementia75)**
2) To suffer from dementia at the age of 95? **(dementia95)**
3) In the absence of advance directives, to be asked to make medical decisions concerning your spouse/partner should he/she become severely ill and unable to make decisions? **(decisions)**
4) That pain (of any origin) can be successfully treated in a situation of imminent dying? **(pain)**
5) That artificial nutrition and hydration helps in a situation of imminent dying? **(artificial)**
6) For a 70-year-old to survive until hospital discharge from a cardiopulmonary resuscitation performed outside of a hospital following a cardiac arrest? **(cardiopulmonary)**
7) That a hospital admission in the case of pneumonia helps for a patient in a situation of imminent dying due to advanced dementia living in a nursing home? **(pneumonia)**
8) That a fourth chemotherapy helps a patient with advanced cancer that three different chemotherapies did not stop? **(chemotherapy)**
9) To die in a nursing home? **(nursing)**
10) To die in a hospital? **(hospital)**
11) To die at home? **(home)**

Figure 1: Average EOL health literacy standardized scores per EOL knowledge and attitudes toward ACP, adults aged 58+, SHARE Switzerland, 2019/2020, n=1,319



Note, the first graph is a binned scatterplots of standardized end-of-life health literacy and knowledge scores, AD = Advance Directives. EOL = End-Of-Life. ACP = Advance Care Planning.

128x171mm (300 x 300 DPI)

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6. Appendices

Appendix 1: List of conference presentations

- **National Congress of Palliative Care 2023**, 22-23.11.2023, Bienne, Switzerland. Oral presentation: “Provision of end-of-life support to loved ones: a crucial determinant of end-of-life health literacy.” Poster presentation: “Overestimation of success rates of CPR is associated with higher preferences to be resuscitated.”

- **16th European Public Health Conference 2023**, 8-11.11.2023, Dublin, Ireland. Oral presentation: “Does physical activity mediate the association of health literacy with cognition in older adults?”

- **Swiss Public Health Conference 2023**, 12-13.09.2023, Lausanne, Switzerland. Oral presentation: “Importance of health literacy and knowledge regarding advance care planning among older adults in Switzerland.”

- **8th International Conference on Advance Care Planning**, 24-27.05.2023, Singapore. Oral presentation: “Importance of health literacy and knowledge regarding advance care planning among older adults in Switzerland.” Poster presentation: “Overestimating success rates of cardiopulmonary resuscitation is associated with higher preferences to be resuscitated: evidence from older adults in Switzerland.” **Best Poster Award - Commendation**.

- **Advance Care Planning Dialogue Workshop**, 27-28.03.2023, Lausanne, Switzerland. Oral presentation: “Importance of end-of-life health literacy and knowledge in care planning among older adults.”

- **Workshop “Cognition, decisions and wellbeing in later life,”** 15-16.12.2022, Lausanne, Switzerland. Poster presentation: “Perceptions and knowledge of end-of-life medical situations among older adults in Switzerland.”

- **GSA 2022 Annual scientific meeting**, 02-06.11.2022, Indianapolis, USA. Oral presentation: “Health literacy among older adults in Switzerland: cross-sectional evidence from a nationally representative population-based observational study” & “End-of-life health literacy: a validation study of a new instrument, the End-of-life Health Literacy Scale(EOL-HLS).”

- **SHARE User Conference**: **Ageing Societies Facing Health, Social and Economic Crises**, 5-7.10.2022, Bled, Slovenia. Poster presentation: “The End-of-life Health Literacy Scale: introduction/development and validation of a new instrument to measure end-of-life health literacy.”

- **7th Public Health Palliative Care International Conference. Democratizing Caring, Dying and Grieving: participation, action, understanding and evaluation**, 20-23.09.2022, Bruges, Belgium. Oral presentation: “End-of-life health literacy: a validation study of a new instrument, the End-of-life Health Literacy Scale (EOL-HLS).” Poster presentation: “Perceptions and knowledge of end-of-life medical situations among older adults in Switzerland.” **Best Scientific Poster Award**.

- **Swiss Public Health Conference 2022**, 13-14.09.2022, Bern, Switzerland. Oral presentation: “Health literacy among older adults in Switzerland: cross-sectional evidence.”

- **National Research Day Palliative Care 2022**, 25.08.2022, Bern, Switzerland. Oral presentation: “Importance of end-of-life health literacy and knowledge in care planning among older adults.”

- **22nd World Congress of Gerontology and Geriatrics (IAGG 2022)**, 12-16.06.2022, Interactive Online Sessions. Poster presentation: “End-of-life health literacy: a validation study of a new instrument, the End-of-Life Health Literacy Scale (EOL-HLS).”

- **12th World Research Congress of the European Association for Palliative Care**, 18-19.05.2022, Interactive Online Sessions. Poster presentation: “Perceptions and knowledge of end-of-life medical situations among older adults in Switzerland.”

- **Les soins palliatifs à travers les humanités médicales**, 15.03.2022, Lausanne, Switzerland. Oral presentation: “Littératie en matière de soins de fin de vie : validation de l’échelle End-of-life Health Literacy Scale (EOL-HLS).”

- **Socio-Economic Perspective on Aging – UNIL-UNIPD Joint Workshop**, 09-10.12.2021, Lausanne, Switzerland. Oral presentation: “Understanding end-of-life care planning decisions in older adults living in Switzerland.”

- **Congrès National des Soins Palliatifs**, 24-25.11.2021, Bienne, Switzerland. Oral presentation: “Perceptions and knowledge of end-of-life medical situations among older adults in Switzerland.”

- **Geneva Aging Series IX**, 01.09.2021, St-Légier, Switzerland. Oral presentation: “SHARE as a multi-purpose data infrastructure for interdisciplinary aging research in Switzerland: Overview and examples.”

- **Swiss Summer Academy Palliative Care Research**, 23-24.08.2021, Mürten, Switzerland. Oral presentation: “Association of health literacy with the approval and completion of advance directive among older adults in Switzerland.”

- **11th International Conference of Panel Data Users in Switzerland**, 10.06.2021, Lausanne, Switzerland. Oral presentation: “Health literacy among older adults in Switzerland.”

Appendix 2: Contributions to additional research papers

List of published articles:

- Iunius L, Vilpert S, Meier C, Borasio GD, Jox RJ, Maurer J. *Advance care planning: a story of trust within the family*. Journal of Applied Gerontology. 2023. (Available from: https://journals.sagepub.com/doi/full/10.1177/07334648231214905?rfr_dat=cr_pub++0pubmed&url_ver=Z39.88-2003&rfr_id=ori%3Arid%3Acrossref.org)

- Meier C, Vilpert S, Carmen Borrat-Besson, Maurer J, Jox RJ. *Perceptions, connaissances et compétences de santé en matière de soins de fin de vie chez les adultes âgés en Suisse*. Les soins palliatifs à travers les humanités médicales. 2023. (Available from: https://www.georg.ch/pub/media/productattach/l/e/les-soins-palliatifs_georg-cms.pdf)

- Vilpert S, Meier C, Carmen Borrat-Besson, Borasio GD, Maurer J. *Préférences, communication et planification des soins de fin de vie chez les adultes âgés en Suisse*. Les soins palliatifs à travers les humanités médicales. 2023. (Available from: https://www.georg.ch/pub/media/productattach/l/e/les-soins-palliatifs_georg-cms.pdf)

- Wieczorek M, Meier C, Kliegel M, Maurer J. *Relationship between low health literacy and unhealthy lifestyle behaviours in older adults living in Switzerland: does social connectedness matter?* International Journal of Public Health. 2023. (Available from: https://www.ssph-journal.org/articles/10.3389/ijph.2023.1606210/full)

- Vilpert S, Meier C, Berche J, Borasio GD, Jox RJ, Maurer J. *Older adults' medical preferences for the end of life: a cross-sectional population-based survey in Switzerland.* BMJ Open. 24 July 2022. (Available from: https://bmjopen.bmj.com/content/13/7/e071444)

- Ryser V-A, Meier C, Vilpert S, Maurer J. *Health literacy across personality traits among older adults: cross-sectional evidence from Switzerland. European Journal of Ageing.* 28 June 2023. (Available from: https://link.springer.com/article/10.1007/s10433-023-00774-x)

- Wieczorek M, Meier C, Vilpert S, Reinecke R, Borrat-Besson C, Maurer J & Kliegel M; *Association between multiple chronic conditions and insufficient health literacy: cross-sectional evidence from a population-based sample of older adults living in Switzerland.* BMC public health. *02 June 2023*. (Available from: https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-023-15136-6)

- Meier C, Maurer J; *Buddy or burden? Patterns, perceptions, and experiences of pet ownership among older adults in Switzerland.* European journal of ageing. *02 April 2022*. (Available from: https://link.springer.com/article/10.1007/s10433-022-00696-0)

List of articles submitted to journals:

- Pigazzini G, Wieczorek M, Meier C, Maurer J; *Healthcare utilization is higher among older adults with inadequate health literacy: cross-sectional evidence from a population-based study in Switzerland*. (Under review to the Journal Swiss Medical Weekly).

Appendix 3: Contribution to research funding proposals

- **Project Funding,** 03.10.2022, Lausanne, Switzerland. Project members: Dr. Maud Wieczorek, Mr. Clément Meier and Prof. Jürgen Maurer. Clément Meier played a crucial role in conceptualizing and drafting the proposal titled "How did COVID-19 reframe end-of-life planning of older adults in Switzerland? Preferences, Communication, Knowledge, and Behaviors Regarding End of Life and End-of-life Planning before and during the COVID-19 crisis," submitted to the SNSF. *The Department of Humanities and Social Sciences of the National Research Council has thoroughly evaluated the proposal. Based on an exhaustive assessment considering external reviews and in alignment with the criteria from the grant regulations, the proposal has been granted a research contribution of CHF 591,840.*

- **Agora – where research meets the public**, 31.08.2022, Lausanne, Switzerland. Project members: Dr. Sarah Vilpert, Clément Meier, Mr. Giuliano Pigazzini, and Prof. Jürgen Maurer. Clément Meier played a pivotal role in conceptualizing and drafting the proposal titled "10 years of advance directives in Switzerland: assessment and public awareness of advance care planning" submitted to the SNSF. *Regrettably, the Agora evaluation panel did not accept the proposal for funding of 49,700 CHF. The primary concerns were related to the clarity and specificity of the content to be communicated, the alignment of the proposed communication methods with the target audience, and uncertainties regarding the project's potential impact. The panel highlighted the need for a more direct engagement mechanism with the public and called for a more coherent communication or social media strategy.*

Appendix 4: Organization of scientific events

- **Advance Care Planning Dialogue Workshop 2023**, 27-28.03.2023, Lausanne, Switzerland. Project members: Dr. Sarah Vilpert, Dr. Maud Wieczorek, Mr. Clément Meier, Mr. Giuliano Pigazzini and Prof. Jürgen Maurer. Clément Meier and the dedicated team meticulously helped organize the workshop. On the 10th anniversary of the law on advance directives in the Swiss Civil Code (2013), the workshop brought together an interdisciplinary ensemble to analyze the trajectory of advance care planning and advance directives in Switzerland. By creating a platform for academic experts from diverse disciplines ranging from medicine, ethics, and sociology to law and economics, along with advance care planning professionals and public health stakeholders, the workshop fostered a comprehensive exploration of the adoption and challenges of advance care planning and advance directives in Switzerland.

- **Les Mystères de l'UNIL 2022**, 18-22.05.2022, Lausanne, Switzerland. Project members: Clément Meier and Dr. Sarah Vilpert. Clément Meier, in collaboration with Dr. Sarah Vilpert, meticulously designed and orchestrated an immersive event for children titled "Dans la peau de ma mamie.” This unique workshop enabled participants to step into the shoes of their grandparents, offering a firsthand experience of the sensory and physical challenges associated with aging. By donning a specialized "aging" suit, glasses, and headphones, children were granted a transformative perspective, highlighting the essence that true empathy often begins with a shift in viewpoint. The event epitomized the adage, "À chaque étape de vie, de nouveaux défis!" encouraging attendees to navigate and appreciate the diverse challenges faced during different life stages.

Appendix 5: SHARE survey’s operational responsibilities

In collaboration with Dr. Carmen Borrat-Besson, Dr. Robert Reinecke, and Prof. Jürgen Maurer, Clément Meier was involved in various operational tasks pivotal for the execution of the SHARE survey:

- Preparing the necessary instruments and translating and testing computer-assisted data collection tools, specifically CAPI and CATI.

- Clément actively participated in international SHARE meetings, both online and in person. Notably, he attended the "SHARE Wave 10 Pretest Meeting" from 3-5 May 2023 in Iaşi, Romania.

- Creating fieldwork documentation. This included drafting contact letters, designing information brochures, and updating the survey manuals.

- Data management and data cleaning, ensuring both the reliability and accuracy of the dataset.

- Preparing training sessions for SHARE interviewers from the survey institute LINK in both the French and German-speaking regions of Switzerland, equipping the interviewers with the essential skills and knowledge needed for effective fieldwork.

- Finally, Dr. Maud Wieczorek and Clément Meier developed a new paper-and-pencil drop-off questionnaire for Wave 10 of SHARE focusing on end-of-life issues. The design of this questionnaire also saw contributions from the SHARE team, the Palliative and Supportive Care Service from the Lausanne University Hospital (CHUV), the Centre for the Interdisciplinary Study of Gerontology and Vulnerability (CIGEV), and the Federal Office of Public Health (FOPH).

Appendix 6: SHARE Wave 8 – Self-administered questionnaire from Switzerland

SHARE
Survey of Health, Ageing and Retirement in Europe
50+ in Europe

Survey of Health, Ageing and Retirement in Europe

2019

Self-administered questionnaire

Respondent ID: ☐☐–☐☐☐☐☐☐–☐☐

Name/Initials: ....

Interview date: ☐☐/ ☐☐/ ☐☐☐☐

IWER-ID: ☐☐☐☐☐

Serial number: ☐

Why this questionnaire?

Self-determination is the ability to decide and act on one's own life. It is a concept that is gaining importance, especially in the medical field. The patient must be informed of the advantages and disadvantages of certain medical treatments for his/her condition and make his/her decision, based on this information. Sometimes, patients may even be able to make these decisions in advance in order to keep control in situations where the person is no longer able to make decisions, as can happen at the end of life. We would like to better understand how you perceive health and medical information, especially with regard to end-of-life issues. We would also like to know whether or not you have made decisions in advance for end-of-life situations. A better understanding of these issues can help to inform health policies regarding the expectations of the population. Thank you in advance for your valuable contribution.

How to complete the questionnaire?

- Mark your answer by placing an “X” in the corresponding box: ☒
- If you make a mistake, fill in the falsely marked box completely and then make a new “X” in the appropriate box for the correct answer: ■ ☒
- Chose only one response per question, unless it is specifically stated that several responses are possible.
- Answer the questions one after the other. Skip a question only if you are asked to.

EXAMPLE

Q73 Are you married?

Yes................................. ☐ 1

No................................. ☐ 2 ➔ **If not, go to question Q76**

If you tick « Yes », go to the following question **Q73**.

If you tick « No », go to the indicated question **Q76**.

YOUR ANSWERS ARE CONFIDENTIAL AND VOLUNTARY.

How to return this questionnaire?

If the interviewer is still in your home when you have completed the questionnaire, please hand it back to him/her. Otherwise, please send it as soon as possible with the postage-paid envelope to:

LINK Institut
Spannortstrasse 7/9
6002 Luzern 2

1 First, we would like to ask you how comfortable you feel when dealing with health-related information.

For you, how easy or difficult is it to…

		Very easy	Fairly easy	Fairly difficult	Very difficult
1a)	find information on treatments of illnesses that concern you?	☐1	☐2	☐3	☐4
1b)	find out where to get professional help when you are ill?	☐1	☐2	☐3	☐4
1c)	understand what your doctor says to you?	☐1	☐2	☐3	☐4
1d)	understand the leaflet that comes with your medicine?	☐1	☐2	☐3	☐4
1e)	understand your doctor's or pharmacist's instructions on how to take a prescribed medicine?	☐1	☐2	☐3	☐4
1f)	judge the advantages and disadvantages of different treatment options?	☐1	☐2	☐3	☐4
1g)	judge when you may need to get a second opinion from another doctor?	☐1	☐2	☐3	☐4
1h)	use information the doctor gives you to make decisions about your illness?	☐1	☐2	☐3	☐4
1i)	follow instructions from your doctor or pharmacist?	☐1	☐2	☐3	☐4
1j)	find information on how to manage mental health problems like stress or depression?	☐1	☐2	☐3	☐4
1k)	understand health warnings about behaviour such as smoking, low physical activity and drinking too much?	☐1	☐2	☐3	☐4
1l)	understand why you need health screenings?	☐1	☐2	☐3	☐4
1m)	judge if the information on health risks in the media is reliable?	☐1	☐2	☐3	☐4
1n)	decide how you can protect yourself from illness based on information in the media?	☐1	☐2	☐3	☐4
1o)	find out about activities that are good for your mental well-being?	☐1	☐2	☐3	☐4
1p)	find out about political changes that may affect your health?	☐1	☐2	☐3	☐4
1q)	understand advice on health from family members or friends?	☐1	☐2	☐3	☐4
1r)	understand information in the media on how to get healthier?	☐1	☐2	☐3	☐4
1s)	judge which everyday behaviour is related to your health?	☐1	☐2	☐3	☐4

2 The medical community uses specialized vocabulary.

We would like to know whether it is easy or difficult for you **to understand** what the following medical terms mean:

		Very easy	Fairly easy	Fairly difficult	Very difficult
2a)	Prognosis	☐1	☐2	☐3	☐4
2b)	Intubation	☐1	☐2	☐3	☐4
2c)	Palliative care	☐1	☐2	☐3	☐4
2d)	Cardiopulmonary resuscitation	☐1	☐2	☐3	☐4
2e)	Artificial nutrition	☐1	☐2	☐3	☐4
2f)	Sedation	☐1	☐2	☐3	☐4

3 Imagine being asked **today** to write down whether or not you would like to receive certain medical treatments in a situation in which you are **no longer able to decide** for yourself (advance directives).

How easy or difficult is it for you to indicate today in writing whether you wish to receive or refuse the following treatments at the end of life?

		Very easy	Fairly easy	Fairly difficult	Very difficult
3a)	breathing machines	☐1	☐2	☐3	☐4
3b)	artificial nutrition	☐1	☐2	☐3	☐4
3c)	blood transfusions	☐1	☐2	☐3	☐4
3d)	antibiotics	☐1	☐2	☐3	☐4
3e)	cardiopulmonary resuscitation	☐1	☐2	☐3	☐4

4 We would like to know how comfortable you feel with the following situations.

For you, is it easy or difficult to…

		Very easy	Fairly easy	Fairly difficult	Very difficult
4a)	define what is **overtreatment** for you?	☐1	☐2	☐3	☐4
4b)	talk about your end-of-life preferences with someone you trust such as a close family member or friend?	☐1	☐2	☐3	☐4
4c)	talk to a physician or other medical expert to learn more about advance care planning tools and end-of-life treatments?	☐1	☐2	☐3	☐4
4d)	find information and/or obtain template forms to complete a so-called “advance directive”?	☐1	☐2	☐3	☐4
4e)	make decisions on whether to accept a treatment or not based on probabilities regarding chances of different treatment outcomes?	☐1	☐2	☐3	☐4
4f)	choose between **comfort care** (relieving suffering without slowing the disease) and **aggressive life-prolonging** treatment (heavy chemotherapy, intensive care with artificial ventilation) should you suffer from a **terminal disease**?	☐1	☐2	☐3	☐4
4g)	define specific conditions or situations in which you would prefer to be left to die?	☐1	☐2	☐3	☐4

5 People differ in their opinion about what is important to ensure they are spending the last months of their lives as best as possible.

How important are each of the following potential end-of-life aspects for you when thinking about **the last six months of life**?

		very important	important	not so important	not important
5a)	Feeling useful to others (giving time, sharing knowledge, etc.)	☐1	☐2	☐3	☐4
5b)	Avoiding being a burden on family	☐1	☐2	☐3	☐4
5c)	Planning the events following my death (funeral, funeral announcement…)	☐1	☐2	☐3	☐4
5d)	Choosing where I die	☐1	☐2	☐3	☐4
5e)	Not dying alone	☐1	☐2	☐3	☐4
5f)	Talking about my fears	☐1	☐2	☐3	☐4
5g)	Receiving spiritual or religious assistance	☐1	☐2	☐3	☐4
5h)	Avoiding overtreatment	☐1	☐2	☐3	☐4
5i)	Having physical contact (e.g. holding hands)	☐1	☐2	☐3	☐4
5j)	Being able to talk or communicate with others	☐1	☐2	☐3	☐4
5k)	Being able to feed myself	☐1	☐2	☐3	☐4
5l)	Using all available medical treatments to prolong life until the end	☐1	☐2	☐3	☐4
5m)	Living without pain	☐1	☐2	☐3	☐4
5n)	Being fully mentally aware	☐1	☐2	☐3	☐4

6 Sometimes personal experiences influence our decisions.

		Yes	No
6a)	Have you ever **made medical decisions** for a person at the end of life who was close to you and who was no longer able to decide for him/herself?	☐1	☐2
6b)	Have you ever **accompanied** (being present, visiting, moral support) a dying relative or close friend?	☐1	☐2
6c)	Have you ever **cared** (personal care, giving medicine, feeding) for a dying relative or close friend?	☐1	☐2

7 Imagine that you experience a cardiac and/or respiratory arrest.
In this situation, you wish ...

☐1 **to be** resuscitated.

☐2 **not to be** resuscitated.

8 Imagine that you are incapacitated following an accident, a stroke, or a heart attack. After initial emergency measures and careful medical assessment, physicians deem it **very unlikely** that you will regain capacity.
In this situation, you prefer ...

☐1 **to forgo** all measures which would only serve to prolong your life and suffering

☐2 that, despite the poor outlook, every medically appropriate measure **should be taken**.

9 Imagine that you suffer from a disease that causes unbearable pain and symptoms such as fear, restlessness, breathing difficulties and nausea.
In this situation, ...

☐1 you wish to receive optimum treatment of pain and other distressing symptoms and you are prepared to **accept the reduced awareness** (sedation) which such treatment may induce.

☐2 for you, **alertness and the ability to communicate** are more important than optimal relief of pain and other symptoms.

10 While some people fully trust certain persons or institutions, other people are apprehensive of them.
With regard to end-of-life issues, to what degree do you trust…

		Completely	Somewhat	A little	Not at all
10a)	relatives	☐$_1$	☐$_2$	☐$_3$	☐$_4$
10b)	physicians?	☐$_1$	☐$_2$	☐$_3$	☐$_4$
10c)	healthcare insurances?	☐$_1$	☐$_2$	☐$_3$	☐$_4$
10d)	the Swiss healthcare system?	☐$_1$	☐$_2$	☐$_3$	☐$_4$
10e)	the Swiss legal system (justice)?	☐$_1$	☐$_2$	☐$_3$	☐$_4$
10f)	religious authorities?	☐$_1$	☐$_2$	☐$_3$	☐$_4$

11 Some people communicate their preferences for the end of their life, while others do not.

Have you ever had a discussion with someone about your wishes for the end of your life?

☐$_1$ Yes
☐$_2$ No **> GO TO QUESTION 13**

12 With whom did you discuss your wishes for the end of life?
Please tick all answers that apply

☐$_1$ Spouse and partner
☐$_2$ Child
☐$_3$ Sibling
☐$_4$ Friend
☐$_5$ Physician
☐$_6$ Other person (*please specify*): ____________________

13 **Advance directives** are a written statement in which an individual can describe his/her preferences for medical treatments and care in case he/she is no longer able to decide by him-/herself. Individuals can also designate someone who can make medical decisions for them if necessary. This written statement is binding for medical providers and relatives.

Have you completed a **written** statement about your wishes and refusals for medical treatments and care (advance directives)?

☐1 Yes **> GO TO QUESTION 16**
☐2 No

14 If you have **not** written a statement about your wishes and refusals for medical treatments and care (advance directives), why is this the case?
Please tick all answers that apply

☐1 I was previously not aware of the existence of advance directives.
☐2 It is too difficult to know what I wish to put in this document.
☐3 I do not think that I need an advance directive, because I think that my family or my physician will make the right decisions on my behalf.
☐4 It is too early for me to make advance directives.
☐5 I am afraid of receiving a lower quality of health care if I have advance directives.
☐6 It is pointless to prepare for a hypothetical situation that one cannot judge well in advance.
☐7 I did not get around to completing one.
☐8 Other reason (please specify): ______________________________

15 How likely is it for you to have a written statement about your wishes and refusals for medical treatments and care some day in the future?

☐1 For sure
☐2 Very likely
☐3 Not very likely
☐4 Certainly not

16 Have you appointed someone **in writing** to make medical decisions for you should you not be able to make those decisions for yourself?

☐1 Yes
☐2 No **> GO TO QUESTION 18**

17 Who did you appoint? *Please tick all answers that apply*

☐1 Spouse and partner
☐2 Child
☐3 Sibling
☐4 Friend
☐5 Physician
☐6 Other person (please specify): ____________________

> GO TO QUESTION 19

18 How likely is it for you to appoint, some day in the future, someone **in writing** to make medical decisions for you should you not be able to make those decisions for yourself?

☐1 For sure
☐2 Very likely
☐3 Not very likely
☐4 Certainly not

19 Do you support the legality of assisted suicide as is currently the case in Switzerland

☐1 Yes
☐2 No

20 Can you imagine circumstances under which you would consider asking for assisted suicide yourself?

☐1 Yes
☐2 No

21 There are associations in Switzerland, such as “Exit” or “Dignitas”, that offer assistance in suicide. Are you a member of such an association?

☐1 Yes **> GO TO QUESTION 23**
☐2 No

22 How likely is it for you to become member of one of these associations some day in the future?

☐1 For sure
☐2 Very likely
☐3 Not very likely
☐4 Certainly not

23 Do you have a spouse or partner?

☐1 Yes
☐2 No **> GO TO QUESTION 30 (page 15)**

24 How well do you think that **you know** your spouse's or your partner's wishes…

		very well	rather well	not very well	not at all
24a)	for the end of life in general?	☐1	☐2	☐3	☐4
24b)	for medical treatment at the end-of-life?	☐1	☐2	☐3	☐4

25 How well do you think that **your spouse or partner knows**…

		very well	rather well	not very well	not at all
25a)	your wishes for the end of life in general?	☐1	☐2	☐3	☐4
25b)	your wishes for medical treatment at the end of life?	☐1	☐2	☐3	☐4

26 We have listed here again end-of-life aspects that may be important to ensure they are spending the last months of their lives as best as possible. We would like you now to report for each of the listed aspects what **your partner or spouse** would consider as very important, important, not so important or not important when **she/he** thinks about the last six months of **her/his life**.
If you don't know, please give us your best estimate.

According to me, **my partner or my spouse** would consider that …

		very important	important	not so important	not important
26a)	feeling useful to others (giving time, sharing knowledge, etc.) is…	☐1	☐2	☐3	☐4
26b)	avoiding being a burden on family is…	☐1	☐2	☐3	☐4
26c)	choosing where she/he dies is…	☐1	☐2	☐3	☐4
26d)	not dying alone is…	☐1	☐2	☐3	☐4
26e)	receiving spiritual or religious assistance is…	☐1	☐2	☐3	☐4
26f)	avoiding overtreatment is…	☐1	☐2	☐3	☐4
26g)	being able to talk or communicate with others is…	☐1	☐2	☐3	☐4
26h)	being able to feed himself/herself is…	☐1	☐2	☐3	☐4
26i)	using all available medical treatments to prolong life until the end is…	☐1	☐2	☐3	☐4
26j)	being without pain is…	☐1	☐2	☐3	☐4
26k)	being fully mentally aware is…	☐1	☐2	☐3	☐4

27 Imagine that **your partner or your spouse** experiences a cardiac and/or respiratory arrest. In this situation, **according to you**, he/she would wish ...

☐1 **to be** resuscitated.
☐2 **not to be** resuscitated.
☐3 I have no idea.

28 Imagine that **your partner or your spouse** is incapacitated following an accident, a stroke or a heart attack. After initial emergency measures and careful medical assessment, physicians deem it **very unlikely** that he/she will regain capacity.

In this situation, **according to you**, he/she would prefer ...

☐1 to **forgo** all measures which would only serve to prolong his/her life and suffering
☐2 that, despite the poor outlook, every medically appropriate measure should be **taken**.
☐3 I have no idea.

29 Imagine that **your partner or your spouse** suffers from a disease that causes unbearable pain and symptoms such as fear, restlessness, breathing difficulties and nausea.

In this situation, **according to you**, ...

☐1 he/she would wish to receive optimum treatment of pain and other distressing symptoms and you are prepared to **accept the reduced awareness** (sedation) which such treatment may induce.
☐2 for him/her, **alertness and the ability to communicate** are more important than optimal relief of pain and other symptoms.
☐3 I have no idea.

30 People have representations of end-of-life medical situations. We would like to know yours.

We would like to know whether you think that the situations described below and related to end-of-life are very unlikely (0-25%), rather unlikely (26-50%), rather likely (51-75%) or very likely (76-100%).
If you don't know, please give us your best estimate.

Example: "In your opinion, what are the chances that it is snowing tomorrow?" If you tick "very likely", you consider that the chances that it is snowing tomorrow range between 76% and 100%.

In your opinion, how likely is it **in general in Switzerland**…

		very unlikely 0-25%	rather unlikely 26-50%	rather likely 51-75%	very likely 76-100%
30a)	to die in a nursing home?	☐1	☐2	☐3	☐4
30b)	to die in a hospital?	☐1	☐2	☐3	☐4
30c)	to die at home?	☐1	☐2	☐3	☐4
30d)	to suffer from dementia at the **age of 75**?	☐1	☐2	☐3	☐4
30e)	that artificial nutrition and hydration helps in a situation of **imminent dying**?	☐1	☐2	☐3	☐4
30f)	that pain (of any origin) can be successfully treated in situation of **imminent dying**?	☐1	☐2	☐3	☐4
30g)	that a hospital admission in the case of pneumonia helps for a patient in situation of **imminent dying** due to advanced dementia living in a nursing home?	☐1	☐2	☐3	☐4
30h)	for a 70-year-old to **survive** until hospital discharge from a cardiopulmonary resuscitation performed outside of a hospital following a cardiac arrest?	☐1	☐2	☐3	☐4
30i)	in the absence of advance directives, to be asked to make medical decisions concerning your spouse/partner should he/she become severely ill and unable to make decisions?	☐1	☐2	☐3	☐4

30 (*Question 30 continued*)
In your opinion, how likely is it **in general in Switzerland**…

		very unlikely 0-25%	rather unlikely 26-50%	rather likely 51-75%	very likely 76-100%
30j)	to suffer from dementia at the **age of 95**?	☐1	☐2	☐3	☐4
30k)	that a fourth chemotherapy helps a patient with advanced cancer that three different chemotherapies did not stop?	☐1	☐2	☐3	☐4
30l)	How likely is it that **you** would accept a fourth chemotherapy in the same situation (advanced cancer that three different chemotherapies did not stop)?	☐1	☐2	☐3	☐4

31 I am a…

☐1 man
☐2 woman

32 I was born in… ☐ *(year)*

33 How easy or difficult was it for you to answer the present questionnaire?

☐1 Very easy
☐2 Fairly easy
☐3 Fairly difficult
☐4 Very difficult

34 Any comments?

Thank you very much for having taken the time to answer our questions.

Please give this questionnaire back to the interviewer or return it by mail using the pre-paid envelope at the survey institute.

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6002 Luzern