Health and Ageing:

Active Ageing in Older Adults and Health Related Quality of Life in People with Dementia

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Abstract

The global aim of this dissertation is to develop a better understanding of two health-related outcomes in the elderly, active ageing (AA) and health-related quality of life (HRQL) in people with dementia. In order to do this, one systematic review and two research articles with population samples were conducted. We have found age, education, occupation and marital status to be associated with AA. According to our review on dementia-specific HRQL, there are at least 15 instruments. Most instruments measure domains such as mood, self-concept, social interaction and enjoyment of activities. Finally, we have found marital status, sex, education and self-rated health to be the most important variables related to HRQL in dementia, whereas dementia severity does not seem to be associated.

Resum

L’objectiu global d’aquesta tesis doctoral va ser aconseguir una millor comprensió sobre dos variables de resultat relacionades amb la salut en geriatria, envelliment actiu (AA) i Qualitat de Vida Relacionada amb la Salut (HRQL) en gent amb demència. Per aquesta raó, una revisió sistemàtica i dos articles de recerca s´han dut a terme. Hem trobat que la edat, educació ocupació i estat civil estan associats amb AA. N’hi han al menys 15 instruments per mesurar HRQL específicament en demència. Aquests instruments inclouen dominis com ara emoció, autoconcepte, interaccions socials i gaudiment d’activitats. Finalment, em trobat que l’estat civil, sexe, educació i salut autopercebuda son les variables mes associades amb HRQL en demència, mentre que la severitat de la demència no ho és.

Preface

On the 1st of June 2008, I joined Dr. Haro's research team at the Parc Sanitari Sant Joan de Deu. Together with 13 more institutions from Spain and other European countries, we would start a four-year project funded by the European Commission as a response to the international policy interest caused by the continuous population ageing in the European Union. The purpose of the project was to complete a study of health in the elderly population with a view on providing strategies for policy makers and practitioners across Europe that were based on valid measures of health, the built environment and the well being of Europe's ageing population. My roles in this group were multiple. I first started participating and organising group meetings to discuss which aspects of health we were going to measure and the scales that were going to be used to measure such aspects. I also participated in the design of the sampling of the study, creating and translating the questionnaire and the manual. The responsibility for creating the database of the study and its codebook was mainly mine. Together with my partner from the Autonomous University of Madrid, we trained the interviewer trainers from all the countries and assisted in the interviewer training in Spain.

I also had the honour of joining Professor Carol Brayne's group at the University of Cambridge. My biggest focus during that one-year stay was on studying a very specific aspect of ageing, health-related quality of life in people with dementia. This is something I deemed very important because dementia is a highly burdening and prevalent disorder in older age, and there is no possible cure to date. I also participated in other studies, especially with my colleague Teddy Cosco, who was conducting a number of systematic reviews on Successful Ageing. Thanks to this last collaboration, I learnt most of what I know about successful ageing. This knowledge made me also want to study successful ageing in the Courage in Europe project. The use of the term "active ageing" in my publications instead of "successful ageing" is due to our partnership with the World Health Organisation.

This dissertation is presented, following the instructions of the Department of Experimental and Health Sciences, as a “compendium of original publications”.

The thesis begins with a research article applying the findings from the reviews on successful ageing conducted at the University of Cambridge to a population study, the COURAGE in Europe Project. This study aims at finding out which variables are associated with AA in a representative sample of Spain, Poland and Finland.

> Perales, J. et al., 2014. Factors associated with active aging in Finland, Poland, and Spain. *International psychogeriatrics / IPA*, pp.1–13.

This dissertation goes further and aims at conceptualising and reviewing which instruments have been used to measure a more specific aspect of successful ageing, HRQL in people with dementia because this disorder is a major challenge for AA. Life quality is also one of the most agreed upon components of AA.

> Perales, J. et al., 2013. Health-related quality-of-life instruments for Alzheimer’s disease and mixed dementia. *International Psychogeriatrics / IPA*, pp.1–16.

Finally, the project presents an analysis of the distribution and correlates of HRQL in people with dementia in a representative sample of the greatly advanced age population of Cambridge.

> Perales, J. *et al.*, 2014. Health-related quality of life in the Cambridge City over-75s Cohort (CC75C): development of a dementia-specific scale and descriptive analyses. *BMC Geriatrics*, 14(1), pp.1–11.

Contents

1. BACKGROUND

1.1 Ageing

a) Worldwide trends in ageing

The continuing growth of older age groups worldwide needs an increased understanding of the ageing phenomena (Population Division, 2011). The primary demographic consequence of fertility decline, especially if combined with increases in life expectancy (determined by the development of lifelong education, biomedical advancements and socioeconomic progress), is population ageing, a process whereby the proportion of older persons in the population increases and that of younger persons declines. Although in developed countries population ageing started early in the XX century, less developed countries began more recently. Therefore, it can be stated that population ageing is a global phenomenon (Fernández-Ballesteros, Robine, Walker, & Kalache, 2013). Table 1 shows the distribution of the world's population and major areas by broad age groups in 2011 and its projections for 2050 and 2100. In 1950, just 8 per cent of the world's population was aged 60 years or over. By 2011, that proportion rose to 11.2 per cent, and it is expected to reach 22 per cent in 2050. Globally, the number of people aged 60 years or over will increase from 784 million in 2011 to more than 2 billion in 2050. Conversely, the number of persons under 15 years of age is projected to remain constant over the next 40 years, slightly increasing from 1.85 billion in 2011 to 1.91 billion in 2050, and their share of the total population will drop from 26.6 per cent in 2011 to 20 per cent in 2050. During the second half of the 21st century, the number of people aged 60 years or over will rise by 600 million to reach 2.8 billion in 2100, and the number of persons under 15 will decrease from 200 million to 1.8 billion in 2100.

Within the older population, the number and proportion of persons aged 80 years or over is rising making it the age group with the fastest population growth. In 2011, there were 109 million people over 80 in the world corresponding to 1.6 per cent of the world population. By 2050, this segment of the population is projected to reach 402 million or 4.3 per cent of the world's population, and by 2100, it will likely rise up to 792 million or 7.8 percent.

Table 1. Distribution of the population of the world and major areas by broad age groups, 2011, 2050 & 2100

	Population in 2011 (millions)						Population in 2050 (millions)						Population in 2100 (millions)					
Major area	0-14	15-24	25-59	60+	80+	Total	0-14	15-24	25-59	60+	80+	Total	0-14	15-24	25-59	60+	80+	Total
World	1852	1213	3125	784	109	6974	1908	1252	4115	2031	402	9306	1814	1225	4255	2831	792	10125
More developed regions	205	156	606	274	54	1240	218	144	531	418	122	1312	226	151	525	433	158	1335
Less developed regions	1647	1058	2519	510	54	5734	1690	1108	3584	1613	280	7994	1588	1074	3730	2398	635	8790
Least developed countries	339	172	295	45	4	851	504	300	740	182	19	1726	565	373	1191	562	110	2691
Other less developed countries	1308	885	2224	465	51	4883	1185	808	2843	1431	262	6268	1023	700	2539	1836	525	6100
Africa	420	209	359	38	5	1046	671	391	914	215	22	2192	763	505	1590	716	136	3574
Asia	1077	753	1949	430	49	4207	899	631	2359	1253	232	5142	728	502	1892	1473	430	4596
Europe	114	91	370	164	32	739	114	75	289	242	67	719	113	76	266	219	79	675
Latin America	164	107	265	61	9	597	129	92	342	188	41	751	107	73	271	236	82	688
Northern America	68	48	165	66	13	348	83	55	188	121	36	447	92	61	209	166	58	526
Oceania	9	6	17	6	1	37	11	7	24	13	3	55	11	8	27	20	7	66

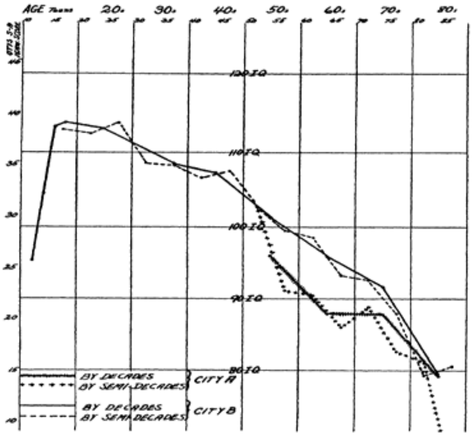
	Percentage distribution by age group																	
World	27	17	45	11	2	100	20	13	44	22	4	100	19	13	46	30	9	109
More developed regions	17	13	49	22	4	100	17	11	41	32	9	100	17	12	40	33	12	102
Less developed regions	29	18	44	9	1	100	21	14	45	20	4	100	20	13	47	30	8	110
Least developed countries	40	20	35	5	0	100	29	17	43	11	1	100	33	22	69	33	6	156
Other less developed countries	27	18	46	10	1	100	19	13	45	23	4	100	16	11	41	29	8	97
Africa	40	20	34	6	0	100	31	18	42	10	1	100	35	23	73	33	6	163
Asia	26	18	46	10	1	100	17	12	46	24	5	100	14	10	37	29	8	89
Europe	15	12	50	22	4	100	16	10	40	34	9	100	16	11	37	31	11	94
Latin America	27	18	44	10	1	100	17	12	45	25	6	100	14	10	36	31	11	92
Northern America	20	14	48	19	4	100	19	12	42	27	8	100	21	14	47	37	13	118
Oceania	24	15	45	15	3	100	20	13	43	24	6	100	20	14	49	36	12	119

Source: Population Division of the Department of Economic and Social Affairs of the United Nations Secretariat (2011). World Population Prospects: The 2010 Revision. New York: United Nations.

b) Historical point of view

Ageing has been traditionally described from a negative perspective both by the scientific community and the general public alike (Hirshbein, 2001; Lupien & Wan, 2004). According to Palmore, there are at least nine major stereotypes that reflect a negative prejudice against elders: illness, impotency, ugliness, mental decline, mental illness, uselessness, isolation, poverty and depression (Palmore, 1990). The scientific community has also traditionally seen ageing as a negative process. Gerontology (the science of ageing) can be traced back to the early 1900s when Stanley Hall and Lillian Martin advocated shifting the study of psychology from the early stages of life towards the later stages of life (Lupien & Wan, 2004). The biggest contributions to gerontology come from psychology, biomedicine and sociology. Negative findings have usually been found for elder groups by these 3 disciplines. Findings in psychology suggested that there was a downtrend in cognitive abilities such as intelligence with age (Miles & Miles, 1932). In these studies, normal ability for older people was defined by comparing children and young adults. An example of this can be seen in figure 1.

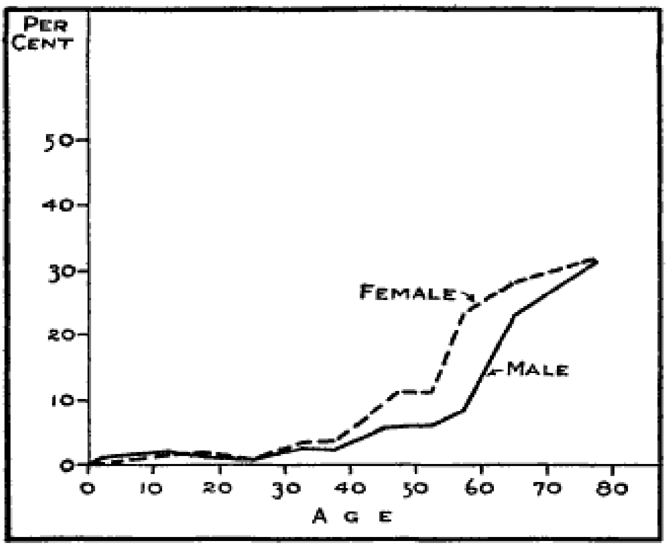
Figure 1. The mean intelligence scores plotted by decades and semi-decades for the populations over 12 years of age studied in two cities with results for both sexes combined.



Source: Miles CC, Miles WR: The correlation of intelligence scores and chronological age from early to late maturity. The American journal of psychology 1932, 44:44–78.

As figure 2 shows, findings from the biomedical disciplines similarly suggested that old age was accompanied by inevitable pathology (Downes, 1941). Findings from sociology during the 1960's lead to the so-called disengagement theory (Cumming & Henry, 1962). According to this theory, older adults withdraw from participation in activity. Elders disengage emotionally from others and from events. Such withdrawal is considered adaptive and beneficial for both the ageing individual and society, as it minimises the social disruption caused by the ageing person's eventual death. However, these studies had a number of caveats. First, these studies were cross-sectional lacking information on longitudinal data. Secondly, comparing the performance between young and old individuals generated a biased definition of normal cognitive ability. Furthermore, there was an emphasis in pathology and disability (biomedical model) (Lupien & Wan, 2004).

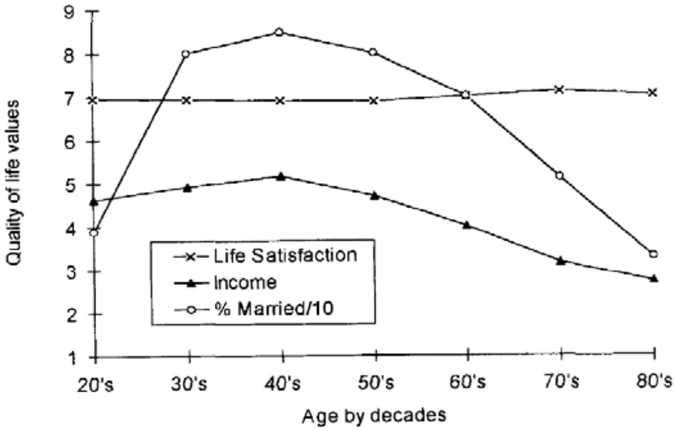
Figure 2. Proportion of the total males and females who reported the presence of chronic disease in 1243 canvassed white families. Eastern Health District of Baltimore, 1938-1939



Source: Downes J: Chronic Disease among Middle and Old-Age Persons. The Milbank Memorial Fund 1941, 19:5–25.

Moreover, from the 1970s onwards, a number of findings began to shed light on a more positive perspective of ageing. While cognitive performance was assumed to be worse in the elderly compared to their younger counterparts, the same comparison between age groups revealed that elders present more variability in cognitive performance (Lupien & Wan, 2004). Despite the steady decline with age of movement, speed, visual acuity and several types of memory, several longitudinal studies found that this decline starts as early as 20 years of age (Lupien & Wan, 2004). Many cognitive skills remain stable or improve with age. Examples of these skills are wisdom, short-term memory, autobiographical memory, semantic memory, knowledge, emotional processing and implicit memory (Baltes & Lindenberger, 1988; Hedden & Gabrieli, 2004). The ageing brain does not lose as many neurons as was once thought, and adult brains continue to sprout new neurons (Barinaga, 2003). Studies have found that age has a U-formed impact of age in life satisfaction: the young are happier than persons around 30 years of age, and thereafter satisfaction with life rises with age (Frey & Stutzer, 2000). Diener concluded after three decades of research that life satisfaction does not decline (figure 3), negative affects do not increase and that even the decline in pleasant emotions might be a cohort effect or due to the exclusive measurement of higher arousal positive emotions (Diener, Suh, Lucas, & Smith, 1999). Elder people seem to navigate interpersonal relationships more adeptly (Helmuth, 2003). In fact, Rowe and Kahn argued that generalising about the elderly was not convenient given the great variability in performance. These authors suggested the differentiation of pathological ageing and successful ageing (Rowe & Kahn, 1997).

Figure 3. Subjective well-being and resources across the adult life span.



Source: Diener E, Suh EM, Lucas RE, Smith HL: Subjective Weil-Being: Three Decades of Progress. *Psychological bulletin* 1999, 125:276–302.

Key points 1.1 Ageing
The continuing growth of older age groups worldwide needs an increased understanding of the ageing phenomena.
Traditionally, there has been a negative vision of ageing both by the scientific community and general public alike.
A number of more recent findings (especially through longitudinal studies) show evidence suggesting that a norm for the elderly is not convenient given the wide variability within this group.
Evidence suggests that features such as happiness, certain types of cognition or management of social relationships can be as good or even better in the elderly compared to their younger counterparts.

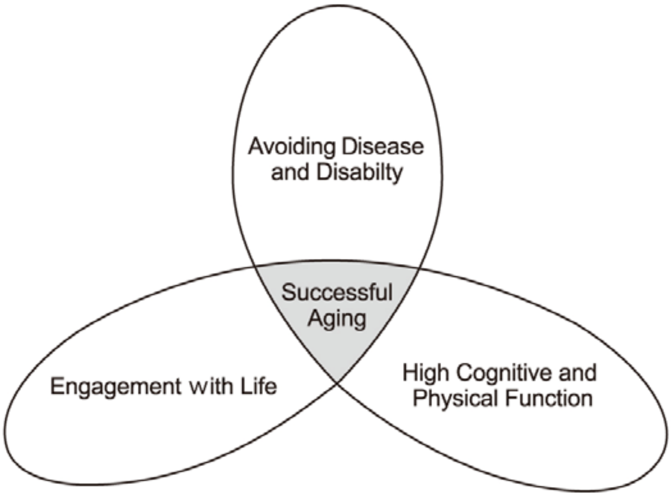
1.2 Active ageing

a) Concept and definitions

Despite the lack of an optimal definition of Active Ageing (AA), the WHO has defined this concept as ‘the process of optimising opportunities for health, participation and security in order to enhance Quality of life (QoL) as people age (Kalache & Gatti, 2003). For most experts in the field, this concept is interchangeable with concepts such as successful (Rowe & Kahn, 1997), productive (Kerschner & Pegues, 1998), positive (Bowling, 1993) and healthy ageing (Guralnik & Kaplan, 1989). However, these terms have specific semantic specifications (Fernández-Ballesteros, Molina-Martínez, Schettini-del-Moral, & Santacreu, 2013). In this text, Active Ageing will be used to represent all these terms.

The most popular definitions of AA are Rowe and Kahn’s model and the model of selection, optimisation and compensation (Baltes & Baltes, 1990; Rowe & Kahn, 1997). Rowe and Kahn conceptualise Active Ageing as the *“Avoidance of disease and disability, maintenance of high physical and cognitive function, and sustained engagement in social and productive activities”* (figure 4). Selective optimization with compensation is a meta-model that explains how individuals make adaptations when faced with changes brought about by the ageing process. According to this model, individuals adjust their expectations to allow the subjective experience of satisfaction and personal control given the restricted options of available functional domains because of an ageing loss in the range of adaptive potential. Optimization relates to the achievement of higher levels of functioning. Compensation refers to processes that occur when other abilities have worsened such as using forward spans in order to compensate for the decrease of reaction times in typewriting (Baltes & Lindenberger, 1988).

Figure 4. Components of AA according to Rowe and Kahn's model.



Source: Successful aging. 1st edition. New York: Pantheon books; 1998:39.

Biomedical, psychosocial and lay perspectives have been used to conceptualise AA (Bowling & Dieppe, 2005). Biomedical theories conceptualise AA mainly through enhancement of longevity while reducing physical and mental decline and disability. These theories put emphasis on freedom from chronic diseases and risk factors for disease; good health, high levels of independent physical functioning, performance, mobility and cognitive functioning. The most popular example of a biomedical model is Rowe and Kahn's, which has been used in the MacArthur studies of successful ageing. These studies were longitudinal epidemiological studies conducted in the community in three different sites in the United States of America in 1988. Psychosocial models focus on satisfaction with life, social functioning, social participation and psychological resources including resilience, personal growth and coping. Its components include life satisfaction, wellbeing, personality and social engagement (Depp & Jeste, 2006). Life satisfaction both present and past has been the most popular and commonly used definition of AA among the psychological theories (Bowling & Dieppe, 2005). Among the social domains, social functioning has been one of the most common domains of AA (Bowling & Dieppe, 2005). Lay perspectives have been used to add domains not usually captured by theoretical models. These perspectives are a result of numerous qualitative studies with elderly people. These include components pertaining to the above-mentioned domains in addition to other components such as having a sense of purpose, financial security and productivity.

There is no consensus on how to operationalise AA. This is in part due to the lack of agreement on how to define the concept. Moreover, there are different ways to operationalise the same components. For example, table 2 shows the different ways cognition has been measured. Some studies used the MMSE while some other studies used other scales or a composite of different neuropsychological tasks. There is also debate about appropriate cut-off points in measures used. As shown in table 2, three different studies have operationalised cognition using all of them the Mini Mental State Examination but while one uses a cut off 18, another one uses 24 and another one the percentile 80 (Depp & Jeste, 2006). Moreover, constituents in some studies (e.g. income, smoking or chronic illnesses) are regarded as factors in others (Bowling & Iliffe, 2006; Strawbridge, Cohen, Shema, & Kaplan, 1996). Regarding the operationalisation of AA, Cosco and colleagues conducted two recent systematic reviews summarising the wide variety of AA operationalisations and contrasting them to lay perspectives of AA in order to develop a unifying model (Cosco, Prina, Perales, Stephan, & Brayne, 2013a, 2013b). His findings suggest that AA is a multidimensional concept as most studies describe and operationalise AA by combining different permutations of physiological, psychosocial and external dimensions. Relying only on, for example physiological factors of AA, is a method that lacks the dynamicity needed to determine the complexity of AA. His findings also suggest that using a wide variety of definitions and methodologies to study AA is not consistent with the way this concept is categorised into active and usual agers. It is elitist to dichotomise active vs. usual agers since only a small number of people will be considered to be ageing actively. However, if AA was operationalised as a continuous measure where people scored higher or lower, all participants would be included to some extent. As a result, it would be possible to conclude that some people age more actively than others. For example, someone with a chronic disease with a good quality of life would be ageing worse than someone with a good quality of life and without the condition but better than someone with a condition and a bad quality of life.

Table 2. Examples of frequency and measurement of components of definitions of AA (29 definitions).

Component	Frequency	Operationalisation
Disability/ physical functioning	26	<20% clinician-rated disability
		>33rd percentile on Grotigen Activity Restriction Scale
		No help with 7 ADLs, 7 IADLs and 3 highly valued activities
		8 activities from health assessment questionnaire
		Mild impairment or better on Older Americans Resources and Services ADL scale
		No ADL disability
		No ADL disability and <1 IADL disability
		Physical ADL-H Scale
		Does not use wheelchair, nor needs help walking outdoors
		Illness or injury imposing limitations on daily life; functional capacity better than peers
		No impairment in 13 activities
		No impairment in 19 activities
		Not in bed or chair most or all day, difficulty bathing, climbing a few flights of stairs, walking several blocks, doing heavy housework
		Self-reported ability to walk quarter mile, climb one flight of stairs, stand up without feeling faint

		No more than a little difficulty in self-reported lifting weights >10 lbs, stooping, crouching, kneeling, pushing or pulling a large object
Cognitive functioning	13	Mini Mental State Examination (MMSE)>18, MMSE>24
		MMSE>80th percentile
		Delayed recall of 3/5
		3MS>78
		Performed well on SPMSQ and Sentence Completion Task
		SPMSQ score >6, 3 > of 6 elements of a short story
		Normal orientation, absence of history of memory problems, Cognitive Abilities Survey score >74
		Seven or more correct on "Mental Status Test"
		Above median on figure analogies, letter series, and practical problems
		Self-reported ability to remember without difficulty and no word- finding difficulty
		Self-rated memory, learning ability, agility good or very good
Life satisfaction/well-being	9	Top 33% or >6 on Cantrill Ladder; GDS <4
		No depressed mood
		Neurgarten 20-item scale >14; never or rarely lonely
		Generally happy, contented, and unworried

		None or one depressive symptom (CES-D)
		Geriatric Depression Scale–15 Item <5
Social/productive engagement	8	Top 33% on Time Spending Questionnaire
		Monthly contact with >3 friends/relatives
		Weekly paying visits to others; participating in outside social activities
		Perceived social support, role variety, occupational status
		Paid employment, caring for child, cleaning house
		>30 hours/week paid work, unpaid work, helping activity
Presence of illness	6	Absence of heart disease, stroke, diabetes, cancer, osteoporosis, emphysema, or asthma, no smoking, hypertension, obesity
		Absence of cancer, cardiovascular disease, chronic obstructive pulmonary disease
		Absence of coronary heart disease, stroke, cancer, diabetes, chronic obstructive pulmonary disease, Parkinson disease
		Number of health problems identified
Longevity	4	Living at age 85
		Alive at time of follow-up
		Survival to age 75
Self-rated health	3	Good or excellent
		Excellent to fair
		General Health Questionnaire 0–5

Personality	2	Extraversion (6-item) and goal strength
		Perceived control
Environment/finances	2	Income and rating of financial security
		Liking home environment, warm enough, no anxiety about intruders or going outside the home
Self-rated successful aging	2	Agreeing strongly to “I am aging successfully”
		Scoring 7–10 on a 1- to 10-point scale

Source: Depp CA, Jeste D V: Definitions and predictors of successful aging: a comprehensive review of larger quantitative studies. The American journal of geriatric psychiatry official journal of the American Association for Geriatric Psychiatry 2006, 14:6–20. (Modified)

b) Distribution and correlates

A systematic review was published in 2006 aiming at reviewing the literature on proportions of subjects meeting criteria for AA as well as their correlates (Depp & Jeste, 2006). This review included studies published between 1978 and 2005. Approximately one third of the elderly subjects sampled met researchers' criteria for AA. A disproportionate variability in the distribution of active agers was found. The range of proportion of active agers varied greatly from 0.4% to 95%. Fairly consistent relationships were found between AA and younger age, not smoking, physical activity, better self-rated health and not having diabetes, arthritis or cognitive impairment. Few relationships with demographic variables such as current marital status, female gender and ethnicity were found (table 3).

Several methodological issues were argued to explain the wide distribution variability. First, definitions of AA varied widely in content and number of components. Domains were varied in most definitions; the only commonalities being disability and functioning. Articles that did not incorporate disability as part of the definition reported a higher percentage of active agers. Second, the vast majority of articles reviewed did not account for longevity only analysing factors associated with active ageing among survivors. Third, some samples consisted of only non-institutionalized populations. Institutionalised populations are more likely to have worse health outcomes. Also, since women are more likely to survive their husbands, unhealthy women are more likely to live in residences. Studies not including institutionalised populations may have underrepresented these people. Fourth, another source of variability was the use of either cutoffs or percentiles to operationalise components of AA. Finally, a predisposition to include negative variables instead of positive ones might also have affected variability in percentages of active agers in the studies reviewed.

The association of AA with younger age found in most studies was explained as being due to the definitions of AA. That is, due to the inclusion of disability as part of the operational definitions. The authors discussed the potential reasons for the lack of association with demographic factors as a methodological issue. Sampling bias may have affected the results in the studies reviewed since for example, people with a lower social position may be less likely to participate in these studies. Another explanation could be that composite variables (AA) might have lessened these associations as compared to individual ones such as disability.

Table 3. Studies finding associations with AA

Demographic factors	Longitudinal	Cross-sectional (n)
Younger age	10/10	3/5
Higher income	2/5	2/4
Education	3/7	1/2
Female gender	4/8	0/2
Male gender	1/1	1/1
White ethnicity	1/4	1/2
Non-white ethnicity	1/1	1/7
Current marriage	0/0	0/3
Better cognitive performance		
Global cognitive function	4/5	1/2
Memory	0/0	1/2
Naming	0/0	1/2
Abstraction	0/0	1/2
Verbal ability	0/0	1/2
Better functional/physical performance		
ADLs/IADLs	4/4	1/1
Grip strength	1/1	2/2
Balance	0/0	2/2
Gait	0/0	2/2
Behavioural factors		
Smoking	7/10	2/2
Alcohol consumption	1/5	1/1
Exercise/physical activity	6/8	0/2

Better self-rated health	2/5	5/5
Biomedical markers		
High-density lipoprotein	1/1	0/1
BMI	2/4	0/1
BP-systolic	1/2	1/2
BP- Diastolic	1/1	0/1
C-reactive protein	2/2	0/0
Ankle arm index	2/2	0/0
Presence of medical conditions		
Number of conditions	2/3	2/4
Diabetes	4/6	1/1
Cardiovascular disease	0/2	0/1
Cancer	1/3	0/0
Hypertension	1/3	1/1
Stroke	1/3	0/1
Arthritis	2/3	1/1
Hearing problems	4/4	0/0
Psychological characteristics		
Depression	2/3	3/4
Life satisfaction	0/1	2/2
Well-being	1/1	2/2
Self-efficacy/mastery/personal control	0/0	2/3
Attitude on ageing	0/0	2/3
Life events	0/0	2/2
Social characteristics	0/0	0/0
Social network size	2/2	2/4

Source: Depp CA, Jeste D V: Definitions and predictors of successful aging: a comprehensive review of larger quantitative studies. The American journal of geriatric psychiatry official journal of the American Association for Geriatric Psychiatry 2006, 14:6–20. (Modified)

Key points 1.2 Active ageing
There is no optimal definition of AA.
There is no consensus on the operationalisation of AA. This is due to the different definitions and the fact that there are different ways to operationalise the same constructs and different cutoffs. However, recent evidence suggests that AA should be operationalised in a multidimensional and continuous way.
AA models have been defined from a biomedical or a psychosocial perspective. These models may be expanded including components suggested by lay individuals.
The percentage of active agers varies widely among studies; this is due to methodological differences among these studies and different conceptualisations of AA.
Younger age, not smoking, physical activity, better self-rated health, not having diabetes, arthritis, or cognitive impairment seem to be associated with AA. Few studies have found associations with demographic variables.

1.3 Dementia: a challenge for Active Ageing

Dementia is one of the most common disorders of old age (Ferri et al., 2005; Marengoni, Winblad, Karp, & Fratiglioni, 2008). Furthermore, it is one of the major causes of disability in later life. It accounts for 5% of the years lived with disability in high-income countries making it the fourth cause of disability. It also accounts for 2.6% of deaths in high-income countries making it the seventh cause of death (Lopez, Mathers, Ezzati, Jamison, & Murray, 2006). It is the leading cause of dependency and disability among older persons in both high-income countries and low and middle income countries (World Health Organization, 2012). All these consequences result in a major challenge for AA in our society.

a) Dementia

Dementia is classified by the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) within the mental and behaviour disorders group, categorised as Organic, including symptomatic, mental disorders under the codes F00-F03 (World Health Organization, 1992). It involves a sustained drop in memory and other intellectual functions occurring in clear consciousness, and changes in behaviour (excess and deficits), emotional control and social functioning. The ICD-10 describes dementia as a syndrome due to disease of the brain, usually of a chronic (over 6 months in duration) or progressive nature, in which there is disturbance of multiple higher cortical functions including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour or motivation (World Health Organization, 1992).

Very little is known about the natural history of dementia. The symptomatology and course of this syndrome varies depending on the underlying diagnosis, the environment and patient characteristics. People with dementia may or may not be aware of their memory loss in the beginning. Sometimes patients complain of feeling depressed instead. Both people with dementia and their relatives may also deny the severity of memory loss and other declines in functioning. Sometimes, dementia is diagnosed after families ask for help because of failing memory, disorientation, self-care, change in personality or behaviour. Some other times, the diagnosis is a result of an incidental finding after investigation of another acute or chronic health problem (Smith et al., 2005). Table 4 shows the most common symptoms of dementia by stage.

It is not possible to predict the course or timescale of cognitive impairment in an individual with dementia other than an overall decrease in function over time. Dementia occurs in Alzheimer's disease, in cerebrovascular disease and in other conditions primarily or secondarily affecting the brain such as Lewy body dementia and frontal or frontotemporal dementia. The boundaries between subtypes are indistinct and mixed forms often co-exist (World Health Organization, 1992). The final dementia subtype diagnosis is usually only possible after the death of the person with dementia by analysing the brain tissue (Smith et al., 2005).

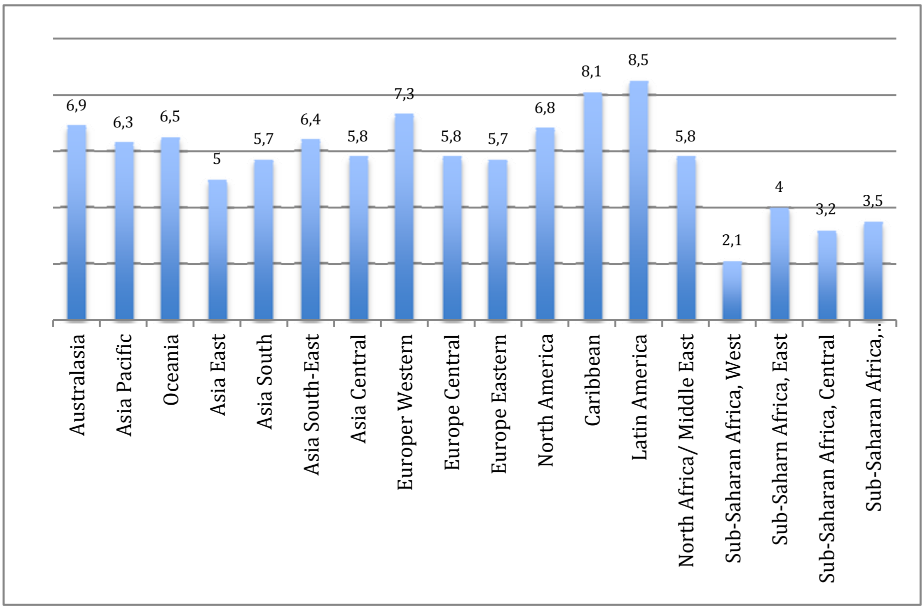
Table 4. Most common symptoms of dementia by stage

Early stage	Middle stage	Late stage
The early stage is often overlooked. Relatives and friends (and sometimes professionals as well) see it as "old age", just a normal part of ageing process. Because the onset of the disease is gradual, it is difficult to be sure exactly when it begins.	As the disease progresses, limitations become clearer and more restricting.	The last stage is one of nearly total dependence and inactivity. Memory disturbances are very serious and the physical side of the disease becomes more obvious.
• Become forgetful, especially regarding things that just happened	• Become very forgetful, especially of recent events and people's names	• Usually unaware of time and place
• May have some difficulty with communication, such as difficulty in finding words	• Have difficulty comprehending time, date, place and events; may become lost at home as well as in the community	• Have difficulty understanding what is happening around them
• Become lost in familiar places	• Have increasing difficulty with communication (speech and comprehension)	• Unable to recognize relatives, friends and familiar objects
• Lose track of the time, including time of day, month, year, season	• Need help with personal care (i.e. toileting, washing, dressing)	• Unable to eat without assistance, may have difficulty in swallowing
• Have difficulty making decisions and handling personal finances	• Unable to successfully prepare food, cook, clean or shop	• Increasing need for assisted self-care (bathing and toileting)
• Have difficulty carrying out complex household tasks	• Unable to live alone safely without considerable support	• May have bladder and bowel incontinence
• Mood and behaviour: – May become less active and motivated and lose interest in activities and hobbies – May show mood changes, including depression or anxiety – May react unusually angrily or aggressively on occasion	• Behaviour changes may include wandering, repeated questioning, calling out, clinging, disturbed sleeping, hallucinations (seeing or hearing things which are not there)	• Change in mobility, may be unable to walk or be confined to a wheelchair or bed
	• May display inappropriate behaviour in the home or in the community (e.g. disinhibition, aggression)	• Behaviour changes, may escalate and include aggression towards carer, nonverbal agitation (kicking, hitting, screaming or moaning) • Unable to find his or her way around in the home

Source: *Dementia: a public health priority*. Geneva: World Health Organization; 2012.

The global prevalence of dementia has been estimated by the Global Burden of Disease and summarised in ADI's 2009 World Alzheimer Report (World Health Organization, 2012). Enhancements included a fully systematic review of the world literature on the prevalence of dementia (1980– 2009) in 21 GBD regions, a critical appraisal of study quality and an attempt, where possible, to generate regional estimates from quantitative meta-analysis. The report shows that the worldwide crude prevalence of dementia in people 60 years old and over is 4.7%. The region with the lowest prevalence of dementia among people 60 years old and over in 2010 was west Sub-Saharan Africa while the region with the highest prevalence was Latin America with an age and sex-specific prevalence of 2.07% and 8.48% respectively. However, most of the estimated age-standardized prevalence figures lie in a band between 5% and 7% (figure 5).

Figure 5. Estimated prevalence of dementia (%) for persons aged 60 and over standardised to Western Europe population by Global Burden of Disease region.

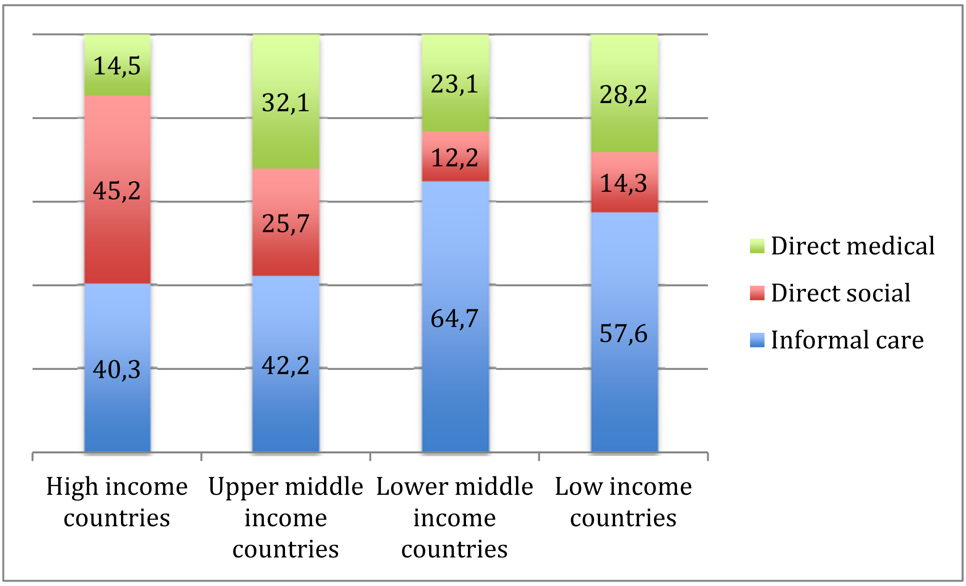


Source: *Dementia: a public health priority*. Geneva: World Health Organization; 2012.

According to these estimations, 35.6 million people worldwide were living with dementia in 2010. The total number of people with dementia is projected to almost double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050. This represents an increase of 85% and 225% from 2010 to 2030 and from 2010 to 2050 respectively. The prevalence of dementia increased exponentially with age in each region doubling with every 5.5 year increment in age in Asia Pacific, Latin America and North America, with every 5.6 year increment in East Asia, every 6.3 years in South Asia and Western Europe, and every 6.7 years in Australasia and South-East Asia. In all regions other than Asia Pacific and North America, the predicted prevalence for men was lower (by 19–29%) than that for women. The worldwide estimation of incidence was nearly 7.7 million new cases of dementia each year implying one new case every 4 seconds. Some 3.6 million (46%) would impact in Asia, 2.3 million (31%) in Europe, 1.2 million (16%) in the Americas and 0.5 million (7%) in Africa.

Evidence shows that dementia is imposing huge economic burdens both through direct (medical and social care) and indirect costs (unpaid caregiving by families and friends) in high, middle and low-income countries (World Health Organization, 2012). As figure 6 shows, the total global societal costs of dementia were US$ 604 billion in 2010. The costs of dementia are unequally distributed. Most (close to 70%) of the global societal costs of dementia occur in North America and Western Europe and almost a 90% of the total costs occur in high-income countries. Nevertheless, around 46% of people with dementia live in high-income countries whereas almost 40% of the population with dementia live in middle-income countries (where 10% of the total costs occur) and 14% in low-income countries (where less than 1% of the total costs occur). The distribution of total costs between sectors also varies markedly by country income level. The costs of informal care and the direct costs of social care are similar in high-income countries (around 40% each). However, in low-income countries and lower-middle-income countries, direct social care costs are small (14%) and informal care costs predominate (57%).

Figure 6: Distribution of total societal costs (%) by World Bank income level.



Source: Dementia: a public health priority. Geneva: World Health Organization; 2012.

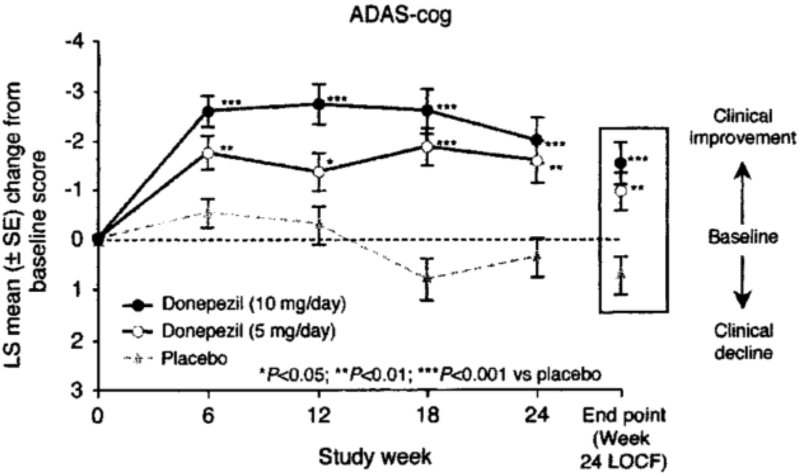
To date, there is no existing cure for dementia. Medications temporarily reduce symptoms for some but without modifying the underlying course of the disorder, which is related to many underlying causes. These are generally prescribed to people in the early and middle stages of the disease (NHS, 2013). There are different types of interventions for dementia. These treatments can be biological, psychological and social.

Medication is the principal type of intervention for dementia. There is evidence of the effectiveness of several medications in treating dementia in its different stages. Acetylcholinesterase inhibitors are licensed to treat mild to moderate Alzheimer's disease and dementia with Lewy bodies being especially useful for hallucinations. Memantine hydrochloride blocks the effects of NMDA-type glutamate receptors. It is licensed to treat severe Alzheimer's disease but can also be used to treat moderate cases where someone does not respond well to acetylcholinesterase inhibitors. Antipsychotics are recommended for severe disruptive behaviour, such as aggression or agitation. This type of medication is rarely recommended for treating dementia, as it might worsen the symptoms. Antidepressants may be prescribed to treat depression related to dementia.

Psychosocial treatments do not slow down the evolution of dementia, but they can help people with dementia cope with the symptoms. An example of psychological interventions is cognitive stimulation. This intervention includes activities and exercises designed to improve memory, problem-solving skills and language ability. Another type of psychological intervention is reality orientation therapy, which is aimed at reducing mental disorientation, memory loss and confusion while improving feelings of self-esteem. Another example is behavioural therapy, which tries to find reasons for difficult behaviour and tries to change it. An example of social treatments is providing home help given that these people might live on their own or with their partner who might need help in taking care of the person with dementia.

Interventions can be delivered at an individual level focused on people with dementia, family carers or service providers. Other interventions may be delivered at a group, community, national or international level (Smith et al., 2005). Interventions have usually focused their assessment on cognition and functional ability (e.g. figure 7). Studies measuring the effects of interventions on cognition have frequently measured this outcome with measures such as ADAS-cog, Mini Mental State Examination and CIBIC-plus (Rogers, Farlow, & Doody, 1998). Functioning has been commonly measured through ADLs and IADLs (S. Black et al., 2003; Rockwood, Mintzer, & Truyen, 2001).

Figure 7: ADAS-cog least squares mean change from baseline score in donepezil and placebo treated patients.

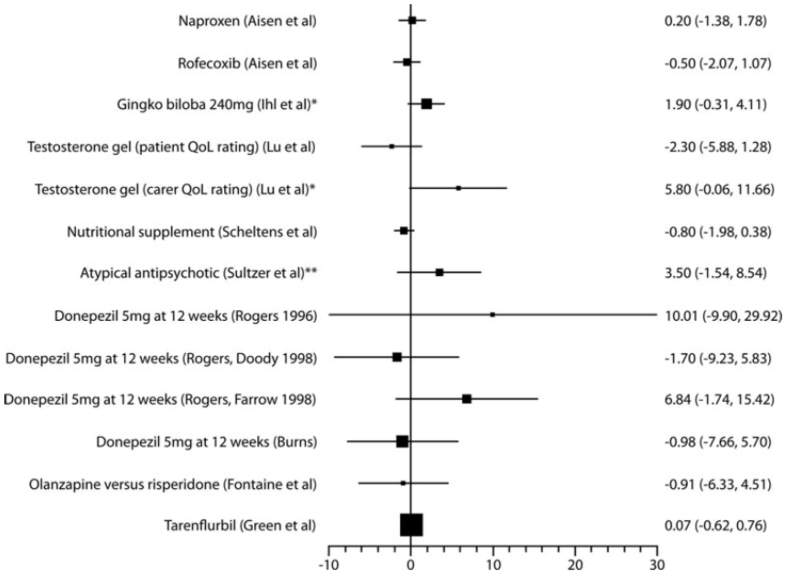


Don 10 mg	n=186	182	162	146	143	186
Don 5 mg	n=186	179	171	154	153	185
Placebo	n=188	187	174	168	160	188

Source: Efficacy and tolerability of donepezil in vascular dementia: positive results of a 24-week, multicenter, international, randomized, placebo-controlled clinical trial. Stroke; a journal of cerebral circulation 2003, 34:2323–30.

However, these outcomes have been deemed insufficient for clinical decision-making and policy development, as they only reflect a part of the impact of dementia (Whitehouse, 2000). Treatment is increasingly focused on improving or maintaining optimal health-related quality of life (HRQL) (Ettema, Dröes, de Lange, Mellenbergh, & Ribbe, 2005), as this has become a key outcome for evaluating the effectiveness of dementia interventions (Moniz-Cook et al., 2008; Small et al., 1997; Whitehouse, 2000). A recent study systematically reviewed 15 randomized controlled trials and one review that fitted predetermined criteria including studies that reported the effectiveness of pharmacologic interventions on HRQL, well-being, happiness or pleasure (figure 8). It was concluded that there was no consistent evidence that any drug improves HRQL in people with dementia (Cooper, Mukadam, Katona, Lyketsos, Blazer, et al., 2012). A similar study systematically reviewed 20 randomized controlled trials reporting the effectiveness of non-pharmacological interventions in improving HRQL or well-being of people with dementia meeting predetermined criteria. It was concluded that coping strategy-based family carer therapy with or without a patient activity intervention improved HRQL of people with dementia living at home. Group Cognitive Stimulation Therapy was the only effective intervention in a higher quality trial for those in care homes, but we did not find such evidence in the community. Few studies explored whether or not effects continued after the intervention stopped (Cooper, Mukadam, Katona, Lyketsos, Ames, et al., 2012).

Figure 8: Metanalysis of pharmacologic interventions for HRQL in dementia. Forest plot of weighted mean differences and 95% confidence intervals.



Source: Systematic Review of the Effectiveness of Pharmacologic Interventions to Improve HRQL and Well-being in People With Dementia. Am J Geriatr Psychiatry 2012.

b) Concept and measures of HRQL of life in dementia

HRQL can be defined as the individual's perception of the impact of a health condition on everyday life (Bullinger, Anderson, Cella, & Aaronson, 1993). It differs from the concept of QoL in that HRQL includes only aspects of HRQL that are affected by a health condition. There is a lack of agreement on what domains constitute HRQL. However, most authors appear to agree upon the multidimensional and subjective nature of the concept and that the assessment should include measurement of positive and negative dimensions (Lawton, 1994; The WHOQOL Group, 1995; Brown et al., 2004; Ready, 2011).

Although the general public and part of the scientific community consider that people with dementia lack life quality, evidence has emerged in the last decades showing that these people can have good HRQL. After a thorough systematic review on the conceptualisation of HRQL, this has been defined as the multidimensional evaluation of the person–environment system of the individual, in terms of adaptation to the perceived consequences of the dementia (Ettema, Dröes, de Lange, Ooms, et al., 2005). However, different authors have conceptualised HRQL in dementia in different ways (Ready, 2011). The work of Lawton on HRQL has had a central influence in all concepts of HRQL in dementia (Lawton, 1994). Lawton characterised QoL as composed by four sectors that comprise the concept: behavioural competence, perceived QOL, objective environment and psychological well-being. Behavioural competence is the social-normative evaluation of the person's functioning in health, cognitive, time use and social dimensions. Perceived QoL is the equivalent to behavioural competence evaluated by the individual. Objective environment refers to physical, social and economic indicators. Finally, psychological well-being is the subjective evaluation of the overall quality of one's experience. According to Lawton, the difference between HRQL in the elderly and in people with dementia is not the theoretical framework but the way these components are operationalised. Table 6 shows the different conceptualisations in health–related HRQL reviewed by Ettema (Ettema, Dröes, de Lange, Ooms, et al., 2005).

A number of measures have been developed specifically for assessing HRQL in patients with Alzheimer's disease or related dementias. These instruments can be either generic HRQL questionnaires used in dementia populations such as the World Health Organization HRQL Assessment (WHOQOL) or Schedule for the Evaluation of Individual HRQL (Schölzel-Dorenbos, 2000; The WHOQOL Group, 1998), dimension specific scales such as the Progressive Deteriorations Scale (PDS) (DeJong, Osterlund, & Roy, 1989) or dementia specific such as the Quality of life in Alzheimer's Disease (QoL-AD) or the DEMQOL (Logsdon, Gibbons, McCurry, & Teri, 1999; Smith et al., 2005). Generic measures cover a broad range of domains such as psychological, physiological and social functioning. These measures often also include domains such as pain, general health perceptions, spirituality, energy or independence (Ettema, Dröes, de Lange, Mellenbergh, et al., 2005). Generic instruments allow for comparisons across different populations (Naglie, 2007). Such measures have, however, been shown to have important limitations. In contrast to dementia specific measures, generic measures are not tailored to people with dementia. Some of these measures are too complex and may not fully capture unique and important aspects of demented people's experiences (Rabins, Kasper, Kleinman, & Black, 1999; Silberfeld, Rueda, Krahn, & Naglie, 2002). Their focus on health domains, including cognitive and physical functioning, imply that HRQL will decrease automatically with disease progression (Ettema, Dröes, de Lange, Mellenbergh, et al., 2005). Furthermore, some of these measures lack evidence on validity or reliability in dementia populations (Ettema, Dröes, de Lange, Mellenbergh, et al., 2005). Dimension specific scales do not focus their measurement in HRQL but only in specific aspects of it. A number of studies have reviewed the different instruments used to measure HRQL in dementia (Ettema, Dröes, de Lange, Mellenbergh, et al., 2005; Lucas-Carrasco, 2007; Ready & Ott, 2003; Ready, 2011; Salek, Walker, & Bayer, 1998; Schozel-Dorenbos et al., 2007; Smith et al., 2005; Walker, Salek, & Bayer, 1998). Table 5 shows the features of the six instruments identified by Ettema (Ettema, Dröes, de Lange, Mellenbergh, et al., 2005).

Several methodological challenges have to be taken into account when measuring HRQL in dementia. The method for obtaining information from people with dementia has to be reliable and valid. In principle, since HRQL is idiosyncratic, self-reports are the most valid source of information. However, obtaining a self-report is not always possible due especially to the severity of the dementia. In general, people with mild to moderate dementia are aware and able to assess their HRQL (Brod, Stewart, Sands, & Walton, 1999; Ready, Ott, Grace, & Fernandez, 2002a). However, the assessment of HRQL in dementia can be complicated by disorders of memory, attention, language, insight, decision making, disorders of behaviour and progression of the disorder (Smith et al., 2005). Proxy-reports and observation are alternatives to this method. Proxy informants have a different point of view on the patient's HRQL and tend to rate it lower than people with dementia (Logsdon, Gibbons, McCurry, & Teri, 2002; Thorgrimsen et al., 2003). This is also the case of observer rating scales. Even with careful training of observers, it is uncertain whether the observed behaviours accurately represent the most important and relevant aspects of HRQL, as HRQL is defined as a person's subjective perceptions. For example, observation based scales usually add items on restlessness and crying in order to infer anxiety and sadness. These are related concepts in different levels (behaviour and mood), but they cannot be assumed to be the same but rather indicators. However, it has been shown that proxies are as good as patients in detecting changes in HRQL over time (Sneeuw et al., 1997). Studies suggest that these differences in reporting can be explained by the disability paradox, caregiver states such as depression or burden and the lack of patient insight (Carr & Higginson, 2001; Logsdon et al., 2002; Novella et al., 2012). These differences can also be explained by methodological issues such as precision bias or response bias which can be minimized by increasing the sample size and by asking proxies to report on observable objective constructs respectively (Smith et al., 2005).

Table 5: Dementia specific instruments to measure HRQL.

Measure	Data collection	Disease severity	Items	Domains	Reliability	Validity	Responsiveness to change
Dementia Care Mapping (DCM)	Trained observers using systematic observation	All stages Mean MMSE in 1 study 8.7		Observed behavioral categories (number varies per patient)	Inter-rater reliability (kappa's > 0.80) Test–retest Spearman correlations from 0.58 to 0.33 on key indices	Some evidence of concurrent validity	Is responsive to change
Alzheimer's Disease Related Quality of Life (ADRQL)	Through interview by trained interviewer of caregiver	All stages	47	Social interaction Awareness of self Enjoyment of activities Feelings and mood Response to surrounding	Internal consistency for total scale (0.80); subscales n.a.	Supported by correlations with disease severity, depression, and behavior disorder	Variation in change scores over a 2 year period detected
Quality of Life for Dementia (QOL-D)	Caregivers	Mild to severe (on Nishimura Mental State scale)	31	Positive affect Negative affect and action Ability of communication Restlessness Attachment with others Spontaneity and activity	Internal consistency (subscales varying from 0.79 to 0.91) Inter-rater (ICC's varying from 0.63 to 0.93)	Correlations with cognitive functioning and ADL scores. Moderate correlations between domains	n.a.
Quality of Life in Alzheimer's Disease (QOL-AD)	Both patient self-report, and caregiver report through interview	Mild to moderate (community dwelling) MSSE > 10	13	Appraisal of: Physical condition Mood Interpersonal relations	Internal consistency (reports from 0.81 to 0.90; 0.83 to 0.90)	Supported by correlations with depression, day-to-day functioning, and	n.a.

				Ability to participate in meaningful activities Financial situation	Test–retest (ICC 0.76 for patients, 0.92 for carers). Patient-carer agreement: (r 0.40 ; ICC 0.19$_{a}$, 0.28$_{b}$)	pleasant events frequency	
Dementia Quality of Life instrument (D-QOL)	Patient self-report through interview	Mild to moderate MMSE > 12	29	Self-esteem Positive affect Negative affect Feelings of belonging Sense of aesthetics	Internal consistency (subscales varying from 0.67 to 0.89) test–retest (0.64 to 0.90)	Evidence of discriminant validity between depressed and non-depressed patients	n.a.
The Cornell–Brown Scale for Quality of Life in Dementia	Clinician interviewing both patient and caregiver	Mild to moderate (tested in outpatients; mean MMSE 22.1)	19	Negative affect Positive affect Physical complaints Satisfactions (weight satisfaction; restful sleep)	Internal consistency for total scale (0.81) Inter-rater (ICC 0.90)	Correlations with visual analogue dysphoria scale	n.a.

Source: Ettema, T.P. et al., 2005. A review of quality of life instruments used in dementia. Quality of life research, 14(3), pp.675–86.

Table 6: Conceptual frameworks of HRQL in dementia.

HRQL domain	Lawton, 1997	Brod et al, 1999	Rabins, 1999	Logsdon, 1999	Ready, 2002	Volicer, 1999	Droes, 1991
Affect	Happiness	Positive affect	Feelings and mood	Mood	Positive affect	Happy-sad mood	Maintaining
	Agitation	Negative affect	Enjoyment of activities		Negative affect	Agitation-calm	
	Depression	Sense of aesthetics				Engagement-apathy	
	Affect state	Feelings of belonging					
	Emotional expression						
	Spirituality						
Self-esteem	Self-esteem	Self-esteem	Awareness of self		Self-esteem		Maintaining a positive self-image
	Life satisfaction						Preparing for uncertain future
	Morale						
(Appraisal of) physical functioning	Self-care abilities			Ability for activities	Satisfaction		Coping with own disability
				Physical condition			
Social relations	Satisfaction with family and friends		Social interactions	Interpersonal relations			Developing and maintaining social relationships
							Developing an adequate care relationship with the staff
							Coping with the institutional environment
(Social) environment	Social engagement		Response to surroundings	Appraisal of financial situation			
	Meaningful time use						
	Physical safety						

	Presence of amenities
	Privacy
	Stimulating quality
	Aesthetic quality
	Satisfaction with spare time and housing (institution) and healthcare
Health	Freedom from barriers
	Behavioural symptoms
	Psychiatric symptoms

Source: Ettema, T.P. et al., 2005. The concept of quality of life in dementia in the different stages of the disease. International Psychogeriatrics, 17(03), p.353.

c) Correlates of HRQL in dementia

A recent study systematically reviewed papers published up to October 2007 on the predictive and explanatory value of measures of HRQL in people with dementia (Banerjee et al., 2009). The variables studied were sociodemographic characteristics such as age, gender and education and clinical characteristics such as insight, cognition and functioning. There was found to be no clear associations between HRQL and socio-demographic characteristics such as age, education and gender. There was very little data on how HRQL in dementia varied with ethnicity. Degree of insight appeared unconnected with HRQL at least in early dementia where one might predict insight to be relatively preserved. There was no data on HRQL and the effect of insight in moderate and severe dementia. Higher caregiver burden was found to be associated with lower ratings of HRQL for self and carer reports, as is carer depression. The QoL of the caregiver has been reported to be associated with the person with dementia's HRQL. Data was not consistent regarding care setting (living in the community, care homes, etc.). Regarding cognition, the absolute level of correlation between severity of cognitive impairment and HRQL is very low. These correlations vary between raters given that staff ratings are generally more associated to HRQL than self-reports and family caregiver reports. However when analysing longitudinal studies, improvement in cognition was found to be associated with improvements in HRQL. Behavioural disorder was found to be associated with decreased HRQL for staff and caregiver ratings but not for self-reports. Strong associations were found for depression with both self and proxy reports of HRQL in mild-moderate dementia but not in people with severe dementia. There were no clear associations between activity limitation and HRQL. When found, these associations where stronger in proxy rating and in severe dementia.

Key points 1.3 Health-related HRQL in dementia
Dementia is one of the most common disorders of old age.
Evidence shows that dementia is imposing huge economic burdens both through direct and indirect costs in high, middle and low-income countries.
To date, there is no existing cure for dementia. Cognition and functioning have been deemed insufficient for clinical decision-making and policy development as they only reflect a part of the impact of dementia.
There are a wide variety of scales to measure HRQL in dementia. These can be divided into domain-specific, generic and dementia-specific HRQL measures and can be self, proxy or observer rated.
Most socio-demographic variables are not associated with HRQL in dementia. There is little evidence on the association between HRQL and cognition or activity. However, depression and behavioural disorders seem to be strongly associated.

1.4 Research questions and objectives

To summarise, the continuous growth of the elderly population has raised international policy interest in promoting AA. There is a lack of consensus on the definition of AA. AA models have been defined from a biomedical or a psychosocial perspective. These models may be expanded including components suggested by lay individuals. There is no consensus on how to operationalise AA either. According to a previous systematic review, the percentage of active agers varies widely ranging from 0.4% to 95%. This is due to several methodological and theoretical reasons. Younger age, not smoking, physical activity, better self-rated health and not having diabetes, arthritis or cognitive impairment seem to be associated with AA. Few studies have researched the associations of AA with demographic variables such as current marital status, female gender and ethnicity.

The study of HRQL in dementia is vital given its prevalence, burden, costs and lack of cure. There are a wide variety of scales to measure HRQL in dementia. There is a lack of evidence on the correlates of HRQL in dementia.

The general objective of this thesis is to provide an insight into the concept of AA and HRQL in dementia, the components, distribution and correlates. The following specific research questions will be addressed:

1. What sociodemographic variables are associated with AA in a representative sample of older adults in Spain, Poland and Finland?

2. What dementia specific HRQL instruments have been developed to date, and what domains do they measure?

3. What is the distribution of HRQL in a representative sample of the oldest old people with dementia in Cambridge?

Consequently, the specific objectives are:

1. To study the distribution and correlates of AA in a representative sample of people from three different European countries, namely, Spain Poland and Finland.

2. To systematically review the evidence on HRQL instruments for dementia providing details of their features, discussing the suitability of the different scales in different contexts and analysing the conceptualisation and operationalisation of each measure.

3. To explore the distribution of dementia specific HRQL by clinical and socio-demographic variables by mapping dementia-specific HRQL in an older age population sample using domains of a validated dementia-specific scale.

2.PUBLICATIONS

2.1. Factors associated with Active ageing in Finland, Poland and Spain.

Perales J, Martin S, Ayuso-Mateos JL, Chatterji S, Garin N, Koskinen S, Leonardi M, Miret M, Moneta V, Olaya B, Tobiasz-Adamczyk B, Haro JM. Factors associated with active aging in Finland, Poland, and Spain. Int Psychogeriatr. 2014 Aug;26(8):1363-75.
DOI: 10.1017/S1041610214000520.

2.2. Health-related quality-of-life instruments for Alzheimer’s disease and mixed dementia

Perales J, Cosco TD, Stephan BC, Haro JM, Brayne C. Health-related quality-of-life instruments for Alzheimer's disease and mixed dementia. Int Psychogeriatr. 2013; 25(5): 691-706.
DOI: 10.1017/S1041610212002293

2.3. Health-related Quality of Life in the Cambridge City over-75s Cohort (CC75C): development of a dementia-specific scale and descriptive analyses

Perales J, Cosco TD, Stephan BC, Fleming J, Martin S, Haro JM et al. Health-related quality of life in the Cambridge City over-75s Cohort (CC75C): development of a dementia-specific scale and descriptive analyses. BMC Geriatr. 2014; 14: 18. DOI: 10.1186/1471-2318-14-18

Perales J, Cosco TD, Stephan BC, Fleming J, Martin S, Haro JM et al. Health-related quality of life in the Cambridge City over-75s Cohort (CC75C): development of a dementia-specific scale and descriptive analyses. Additional files. BMC Geriatr. 2014; 14: 18. DOI: 10.1186/1471-2318-14-18

3. DISCUSSION

This dissertation is composed of our knowledge regarding AA and one of the major challenges for AA, dementia-specific HRQL. One review of the literature and two manuscripts on the distribution and association of these two concepts have been conducted for this purpose. On the one hand, for the achievement of the principal aims, we have analysed the distribution and correlates of AA in a representative sample of people from three different European countries (Perales, Martin, et al., 2014). On the other hand, this thesis summarises the available evidence on the existing dementia-specific HRQL instruments and their metric properties (Perales, Cosco, Stephan, Haro, & Brayne, 2013) discussing the suitability of the different scales in different contexts and analysing the conceptualisation and operationalisation of each measure. Finally, we have explored the distribution of HRQL in dementia by clinical and socio-demographic variables by mapping dementia-specific HRQL in an older age population sample using domains of a validated dementia-specific scale (Perales, Cosco, et al., 2014).

3.1. What sociodemographic variables are associated with AA?

a) Differences in AA between the 3 countries

Significant country differences were found in all the definitions of AA with Poland having the lowest score, followed by Spain and Finland. Similar trends have been reported in the SHARE project (Hank, 2011) in which Poland was the one, among 14 Europeans countries, with the least active agers using Rowe and Kahn's definition (1.6%), followed by Spain (3.4%). Nordic-European countries such as Denmark (21.1%) and Sweden (17.4%) were the countries with the highest percentage of active agers. In our study, when analysing the different AA components by country, Poland comes last in nearly every component. Poland has the highest percentage of disability, current smokers and sedentary lifestyle and the lowest percentage of high cognition, social participation, social contacts, control, coping and environmental safety. Finland, on the other hand, has the best rates in most components. Although Spain is in a middle stage regarding AA components, it is worth highlighting the percentage of illiteracy and low education and occupation roles in the country. Whereas there is almost no illiteracy in the other two countries, almost one in every ten Spaniards aged 50 years and over is illiterate. More than three out of ten did not complete primary school compared to less than four percent in Poland and less than two in Finland. This is especially important given the associations between education and occupation and AA.

Table 7. Percentages Meeting Specific "Successful Aging" Criteria By Country in the Share project

	AT	DE	SE	NL	ES	IT	FR	DK	GR	CH	BE	IL	CZ	PL	IE	ALL
No major disease	59.0	47.5	45.2	49.8	40.3	39.0	39.3	51.0	48.1	59.6	46.4	31.5	41.2	25.5	42.6	42.6
No disability	88.0	84.2	86.8	88.8	85.3	83.8	83.5	85.9	88.7	90.8	81.7	83.0	88.2	67.0	83.5	83.7
High cognitive functioning	68.4	67.5	64.8	63.4	20.9	36.3	45.3	67.2	53.2	70.9	52.5	44.2	60.2	30.5	60.8	48.5
High physical functioning	64.6	61.4	68.5	69.4	51.4	54.2	60.6	69.4	49.5	79.0	62.6	42.3	59.0	31.1	64.7	57.3
Actively engaged	22.3	27.4	39.7	40.7	22.8	24.2	29.5	42.6	27.0	31.4	37.5	35.1	18.0	17.1	40.6	27.1
Successful ageing (global)	10.2	11.6	17.4	17.0	3.1	5.3	8.4	21.1	7.7	16.1	11.8	10.2	6.4	1.6	15.7	8.5

AT = Austria; DE = Germany; SE = Sweden; ES = Spain; IT = Italy; FR = France; DK = Denmark; GR = Greece; CH = Switzerland; BE = Belgium; IL = Israel; CZ = Czech Republic; PL = Poland; IE = Ireland.

Source: Hank K (2011) How "successful" do older Europeans age? Findings from SHARE. The Journals of Gerontology Series B: 230–236.

b) Factors associated with AA

In our study, age, education, marital status and occupation were the most important factors associated to AA. Specifically, growing old was associated with lower scores on almost all models of AA. This result is consistent with ten out of ten longitudinal and three out of five cross-sectional studies reviewed by Depp and Jeste (Depp & Jeste, 2006). The lack of associations with age in the psychosocial definition is consistent with the idea that the elderly can do as well, or some times even better, than young people regarding happiness or managing social relationships (Carstensen, 2006; Helmuth, 2003). There is also evidence that supports our finding that socio-economic position was associated with AA (Hank, 2011; Jeste et al., 2013; Strawbridge et al., 1996). In our study, both education and occupation were independently associated with AA. Different mechanisms could be contributing to these associations. According to neo-material theories, a lower socio-economic position would be linked to having fewer resources to avoid risks, cure illnesses, prevent diseases and living in a more deprived and unsafe environment. Behavioural theories explain this phenomenon by means of an increase in cognitive skills or information through education that can enhance health behaviours and thus also prevent disease and increase quality of life. Finally, the psychosocial theories stress the idea of social comparison and the sense of lack of control of one's own life among those with a lower position. Being currently married or cohabiting was associated to higher AA scores compared to being widowed, divorced or even never married in different definitions of AA. Only one out of seven longitudinal studies and none out of three cross-sectional studies found current marriage to be associated with AA in a recent systematic review (Depp & Jeste, 2006). The associations with marital status could be related to social support mechanisms given that one of the primary benefits of marriage is social connectedness or more instrumental aspects of marriage such as finances.

c) Implications

These findings have implications for public health policies. There are numerous aspects in which the three countries could promote AA. This can be achieved by reducing inequalities in education and occupation in these three countries because they have been consistently associated with AA. Alternatively, measures can be taken to increase AA by improving individual components of active ageing directly. Poland, for example, should aim at tackling disability among other aspects. According to the WHO International Classification of Functioning Disability and Health (ICF) (World Health Organization, 2001), in order to decrease disability, interventions should be aimed at the environment and not only focusing on the individual's functioning. In the case of Spain, special emphasis should be put on education and reducing gender differences. Even though education in Spain is now compulsory until age 16, cuts are currently being implemented in education to the extent that the budget for education has decreased 31.6% from 2011 to 2013 (Presupuestos Generales del Estado, 2011, 2013). Also, tuition fees are being increased in universities due to the economic crisis (Diari Oficial de la Comunitat Valenciana, 2011, 2012). This is a threat to AA for future generations given the consistent education gradients across all definitions of AA. Gender inequalities have been found specifically for Spain. Despite being the country with more active agers, Finland can still benefit from tackling social inequalities. Chronic conditions, alcohol consumption and social support are areas in which Finland could focus their efforts. Further studies should focus on aspects related to support in people who are not married or cohabiting and the factor's association with AA, as these people show lower levels of AA in the three countries. The associations found may vary depending on gender. Future research will be necessary to shed light on this issue.

3.2. What dementia specific HRQL instruments have been developed to date and what domains do they measure?

a) HRQL instruments for dementia

In the last decades, not only generic HRQL measures have been used in dementia patients (Novella et al., 2012; Schölzel-Dorenbos, 2000) but also at least 15 disease-specific scales have been developed (Perales et al., 2013). These scales are the following: Alzheimer Disease Related Quality of Life (ADRQL), Bath Assessment of Subjective Quality of Life in Dementia (BASQUID), Cornell-Brown Scale for Quality of Life in Dementia (CBS), Dementia Care Mapping (DCM), Dementia Quality of Life Instrument (D-QoL), DEMQOL, Patient Activity Scale-AD plus the Modified Apparent Emotion Scale (PES-AD + AES), Quality of Life in Late-stage Dementia Scale (QUALID), QoL-AD, Quality of Life Assessment Schedule (QOLAS), Quality of Life for Dementia (QoL-D), QUALIDEM, Quality of Life for Older People Experiencing Dementia (QLDJ), Vienna List, and the Community Dementia Quality of Life Profile.

b) Conceptualisation and operationalisation

The current concept of HRQL in dementia has been influenced by the broader concept of QoL that refers to “evaluation by subjective and social-normative criteria, of the behavioural and environmental situation of a person” (Lawton, 1994). In the last decades, there has been a movement in QoL towards a more idiosyncratic measurement; this is the measurement of the experience of the person. Measurements typically include perceptions or satisfactions with psychological, physical and social domains (Ettema, Dröes, de Lange, Ooms, et al., 2005). This is also true for dementia-specific HRQL instruments since the measurement is also aimed at assessing the experience of the person with dementia. The most frequently measured domains are mood, self-esteem, social interaction and enjoyment of activities. Something in common with the general concept of QoL is that normative measures such as income or cognitive tests (different to perception or satisfaction with such domains) have been excluded from these measures and regarded as a different outcome (B. S. Black, Rabins, & Kasper, 1999; Brod et al., 1999).

There is not much of an essential difference between the conceptual frameworks used to develop the dementia-specific HRQL instruments and Lawton’s model of HRQL in dementia (Lawton, 1994). The biggest difference would be the limitation of dementia HRQL measures in the number of domains. There are different perspectives on HRQL. These different perspectives can be seen in the variety of domains represented in the different instruments. A difference between the instruments is the breadth the assessment and whether HRQL is assessed via self-report or proxy (observational or not). Self-reported measures are more suitable for assessing the person’s own experience. However, in severe stages, the use of instruments based on proxy ratings is necessary.

c) Country of development and validation

Most dementia-specific HRQL measures to date have been developed in the USA and UK. A number of scales have been validated in other countries (Matsui et al., 2006; Suzuki, Uchida, Kanamori, & Ooshiro, 2005) increasing the availability of these measures in other countries. The QoL-AD has been the most widely validated instrument so far being validated in at least ten different countries. The D-QoL has also been validated in a number of countries in the Americas, Europe and Asia. While validating instruments allows for cross-country comparisons, the concept of HRQL may differ across different cultures. Therefore, culturally specific scales may also be necessary. None of the 15 instruments found in our review have been developed or validated using a population-based sample raising issues of the generalizability of these constructs and measures.

d) Dementia severity

Dementia severity will guide which scale should be used. For mild-moderate stages, self-rated instruments would be the most suitable. For severe stages of dementia, proxy and observer-rated instruments are necessary.

Most of the extant dementia-specific HRQL measures are proxy rated. This is a consequence of the idea that people with dementia are not able to rate their own HRQL due to cognitive impairment. However, more recent instruments have started to obtain self-reports from the individual with dementia when possible given that it has been suggested that people with mild-moderate dementia are aware and able to assess their HRQL (Brod et al., 1999; Logsdon et al., 2002; Mozley et al., 1999; Ready, Ott, Grace, & Fernandez, 2002b; Selai, Trimble, Rossor, & Harvey, 2001; Smith et al., 2005; Richard Trigg, Jones, & Skevington, 2007). What is more, evidence shows that proxy informants' perspectives differ from those of people with dementia. Proxy informants tend to rate the patient's HRQL lower than people with dementia (Logsdon et al., 2002; Thorgrimsen et al., 2003). Even with careful training of observers, it is not clear whether the observed behaviours represent the most important and relevant aspects of HRQL, as these measures have been developed to assess the subjective perceptions of QoL. However, proxies seem to rate changes in HRQL over time similarly to people with dementia (Sneeuw et al., 1997). Differences in reporting HRQL between people with dementia and proxy informants/observers can be explained by the disability paradox, caregiver states such as depression or burden and the lack of patients' insight (Carr & Higginson, 2001; Logsdon et al., 2002; Novella et al., 2012). Methodological issues such as precision bias or response bias (Smith et al., 2005) may also account for these differences. The most appropriate approach, if possible, would be to obtain information from both sources (patients and caregivers) or assessing HRQL using different instruments covering all dementia severities (Edelman, Fulton, Kuhn, & Chang, 2005).

e) Purpose of assessment

The purpose of assessment is also important when selecting the most suitable instrument. When the assessment of HRQL in dementia is needed for clinical practice, the most suitable scale will let the person with dementia assess a personal perception of HRQL. Assessing HRQL with this type of scale will allow a more personalised, and therefore effective, treatment plan. To date, there is only one scale that allows this type of assessment, the QOLAS (Selai et al., 2001). This is a double edged sword since a disadvantage of this scale in research is that, for this same reason, scores of the different participants or the same participant in different stages might not reflect the same concept of HRQL, and therefore, comparisons do not seem to be completely pertinent.

Operationalisation, country of development/validation and data collection methods will guide the selection of the scale in studies of cross-sectional nature. For longitudinal studies, proxy and observer-rated scales are more appropriate, as severity of dementia is likely to increase over time. Responsiveness is a key factor in longitudinal and randomized control trials. The BASQID, QoL-AD, ADRQL, QUALID, PES-AD+AES, and DCM (Albert et al., 2001; B. S. Black et al., 1999; Fossey, Lee, & Ballard, 2002; Martin-Cook, Hynan, Rice-Koch, Svetlik, & Weiner, 2005; Thorgrimsen et al., 2003; R Trigg, Skevington, & Jones, 2007) have proved to have a certain degree of responsiveness.

f) Psychometric properties

In general, most measures showed good psychometric properties. The majority of scales showed good evidence of internal consistency, and most measures have at least tested reliability in two different ways. All self-rated instruments and one scale of each of the other data collection methods showed at least some good evidence of acceptability. Qualitative evidence from pretesting with patients, expert opinion and literature review has been used to reach at least a certain degree of content validity. Instruments such as the D-QoL, DEMQOL, BASQID, ADRQL, QUALIDEM, and QoL-D obtained qualitative evidence from both patients and/or their carers in order to generate the items. A special case is the QOLAS in which the items are tailored to each respondent. In order to test convergent validity, correlations between the scales and different measures such as dementia severity, depression, activities of daily living, behavioural and psychological symptoms and other measures of QoL have been analysed. Discriminant has been assessed by means of associations with gender, age or caregiver characteristics. However, this last property has been scarcely tested.

3.3. What is the distribution of HRQL in a representative sample of the Oldest old people with dementia in Cambridge?

We have assessed the distribution of HRQL in very old individuals with mild-moderate dementia, a section of the population with whom it is hard to conduct this kind of research. Marital status, sex, education and self-rated health seem to be the most important variables related to HRQL. Dementia severity does not seem to be associated with HRQL in dementia.

Findings such as the lower HRQL in men with dementia who are 90 years of age and older compared to younger groups may be due to differential mortality between gender (Raleigh & Kiri, 1997). The oldest age group is likely to have worse health than the other two age groups. The established relationship between married state and higher HRQL in men is found for men with dementia, too. This could be related to social support mechanisms given one of the primary benefits of marriage for men is social connectedness (Umberson, Wortman, & Kessler, 1992). According to the sex role hypothesis, this positive effect of marriage would not affect women because of the ungratifying nature of housework and the normative that women are primarily responsible for household chores (Gove & Tudor, 1978; Kessler & JA, 1981). People with moderate dementia severity who left school after age 14 had a very low HRQL score compared to those with the same level of education but higher cognition and to those who left school before that age. This could be related to the cognitive reserve hypothesis (Stern, 2009). There is evidence showing that high cognitive reserve groups have a higher cognitive decline though later (Stern, Albert, Tang, & Tsai, 1999; Teri, McCurry, Edland, Kukull, & Larson, 1995). A systematic review found cognitive decline to be associated to HRQL (Banerjee et al., 2009). Patients with high reserve and moderate dementia might be more worried about the sudden decline of their functioning compared to the other groups. This may also reflect that this group is more conscious of their limitations in relation to more intellectual tasks, e.g. reading for pleasure, than people with less formal education who may be less troubled by such impairments.

These results have practical implications for public health policies and dementia care. They emphasise the need for taking gender into account when assessing and implementing programmes to improve HRQL. According to the present findings, improving social support and modifying sex roles that can decrease HRQL when affected by dementia such as women’s family tasks will be key in these programmes.

4. CONCLUSIONS

1. Gradients in age, education and occupation suggest that these may be important factors related to AA.

2. Gender and urbanicity do not seem to be associated with AA.

3. The association patterns of AA vary across countries, especially regarding gender and marital status.

4. Finland has the highest scores in AA followed by Spain and Poland.

5. At least 15 disease-specific instruments exist designed to evaluate health-related quality of life in people with dementia.

6. The suitability of HRQL scales depend on several factors:

> -Country of validation: It is important that the instrument has been validated in the country where HRQL will be assessed.
>
> -Dementia severity: Proxy and self-reports are complementary since they both reflect different and imperfect measurements of "true" state. However, in people with mild-moderate dementia severity, self-rated instruments are preferred, as evidence shows that these people are aware and able to assess their HRQL (subjective by nature). People with severe dementia are not and therefore proxy or observer ratings are to be used.
>
> -Purpose of assessment: For clinical practice, the optimal instrument is the one where the items can be tailored to each respondent. For longitudinal assessments, instruments that are proxy/observer rated and are sensitive to change are preferred.

-Conceptualisation: Not all HRQL instruments for dementia measure the same domains. It is important to select the instrument that best reflects what one wants to measure.

-Psychometric properties: Most instruments show good reliability and validity. Important properties are responsiveness and whether the items of the instrument were created through in-depth qualitative interviews with patients and their carers.

-Scoring: Subscales may be useful for treatment purposes whereas total scores are more useful for research. The optimal scale will measure both.

5. Marital status, gender, education and self-rated health seem to be the most important variables related to HRQL.

6. Dementia severity itself does not seem to be associated with HRQL in dementia.

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6. APPENDIX: OTHER COURAGE PUBLICATIONS

Caballero, F. F., Miret, M., Olaya, B., **Perales, J**., López-Ridaura, R., Haro, J. M., Chatterji, S., Ayuso-Mateos, J. L., 2013. Evaluation of Affect in Mexico and Spain: Psychometric Properties and Usefulness of an Abbreviated Version of the Day Reconstruction Method. *Journal of Happiness Studies*.

Abstract

The aims of the present study were to assess the psychometric properties of the Spanish-language version of the abbreviated Day Reconstruction Method (DRM), and to investigate differences in affective experience in Mexico and Spain. A total of 2,629 adults from Mexico and 4,583 from Spain were interviewed. Information was obtained using an abbreviated version of the DRM, which had been translated into Spanish. Reliability, validity, and the structure of affect were assessed and compared between countries. The diurnal variation of affect, the changes in affect along the life span, time use, and the relationship between affect and socio-demographic characteristics were also analysed. Adequate psychometric properties for the Spanish-language version of the abbreviated DRM were found in both the Mexican and the Spanish samples, and affect tended to improve along the life span in both countries. However, net affect did not have the same distribution function (Kolmogorov–Smirnov statistic = 0.25, $p < 0.001$) in both countries, being higher in Spain. Moreover, both samples showed opposite patterns in the diurnal variation of affect. The results showed that the Spanish-language version of the DRM is a feasible and valid method to measure affect, its diurnal rhythms, and time use in large-scale surveys.

Garin, N., Olaya, B., **Perales, J**., Moneta, M. V., Miret, M., Ayuso-Mateos, J. L., Haro, J. M., 2014. Multimorbidity patterns in a national representative sample of the Spanish adult population. *PloS one*, 9(1), p.e84794.

Abstract

BACKGROUND: In the context of population aging, multimorbidity has emerged as a growing concern in public health. However, little is known about multimorbidity patterns and other issues surrounding chronic diseases. The aim of our study was to examine multimorbidity patterns, the relationship between physical and mental conditions and the distribution of multimorbidity in the Spanish adult population. METHODS: Data from this cross-sectional study was collected from the COURAGE study. A total of 4,583 participants from Spain were included, 3,625 aged over 50. An exploratory factor analysis was conducted to detect multimorbidity patterns in the population over 50 years of age. Crude and adjusted binary logistic regressions were performed to identify individual associations between physical and mental conditions. RESULTS: Three multimorbidity patterns rose: 'cardio-respiratory' (angina, asthma, chronic lung disease), 'mental-arthritis' (arthritis, depression, anxiety) and the 'aggregated pattern' (angina, hypertension, stroke, diabetes, cataracts, edentulism, arthritis). After adjusting for covariates, asthma, chronic lung disease, arthritis and the number of physical conditions were associated with depression. Angina and the number of physical conditions were associated with a higher risk of anxiety. With regard to multimorbidity distribution, women over 65 years suffered from the highest rate of multimorbidity (67.3%). CONCLUSION: Multimorbidity prevalence occurs in a high percentage of the Spanish population, especially in the elderly. There are specific multimorbidity patterns and individual associations between physical and mental conditions, which bring new insights into the complexity of chronic patients. There is need to implement patient-centered care which involves these interactions rather than merely paying attention to individual diseases.

Raggi, A., Quintas, R., Russo, E., Martinuzzi, A., Costardi, D., Frisoni, G. B., Franco, M. G., Andreotti, A., Ojala, M., Peña, S., **Perales, J**., Chatterji, S., Miret, M., Tobiasz-Adamczyk, B., Koskinen, S., Frattura, L., Leonardi, M., 2013. Mapping SAGE questionnaire to the International Classification of Functioning, Disability and Health (ICF). *Clinical psychology & psychotherapy*.

Abstract

The collaborative research on ageing in Europe protocol was based on that of the World Health Organization Study on global AGEing and adult health (SAGE) project that investigated the relationship between health and well-being and provided a set of instruments that can be used across countries to monitor health and health-related outcomes of older populations as well as the strategies for addressing issues concerning the ageing process. To evaluate the degree to which SAGE protocol covered the spectrum of disability given the scope of the World Health Organization International Classification of Functioning, Disability and Health (ICF), a mapping exercise was performed with SAGE protocol. Results show that the SAGE protocol covers ICF domains in a non-uniform way, with environmental factors categories being underrepresented, whereas mental, cardiovascular, sensory functions and mobility were overrepresented. To overcome this partial coverage of ICF functioning categories, new assessment instruments have been developed. KEY PRACTITIONER MESSAGE: Mapping exercises are valid procedures to understand the extent to which a survey protocol covers the spectrum of functioning. The mapping exercise with SAGE protocol shows that it provides only a partial representation of body functions and activities and participation domains, and the coverage of environmental factors is poor. New instruments are therefore needed for researchers to properly understand the health and disability of ageing populations.