Research in very old age: Challenges of studying well-being and its predictors in centenarians

Daniela S. Jopp

UNIL | Université de Lausanne

Overview

- Why study the oldest-old?
- What are specific challenges?
- What could be potential solutions?
- Summary and discussion

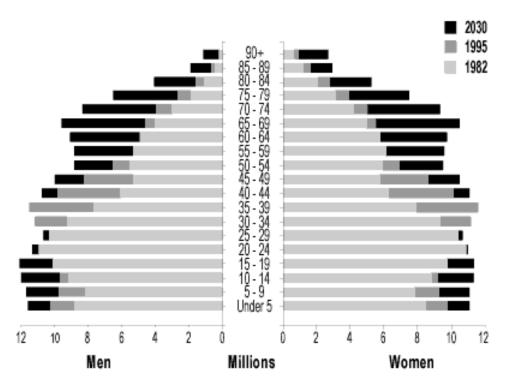
Structure

- 13:30 14:15 Block 1: Centenarian Findings
- 14:15 14:45 Coffee Break
- 14:45 15:45 Block 2: Issues with Centenarian Research
- 15:45 16:15 General Discussion

Why Study the Oldest-Old?

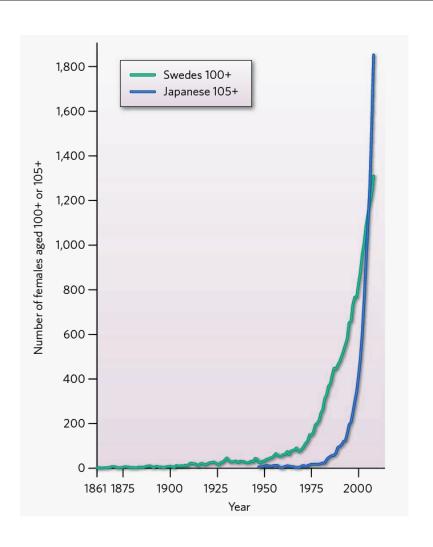
In the US and other Western countries, life expectancy is increasing continuously.

Expanding Aging U.S. Population

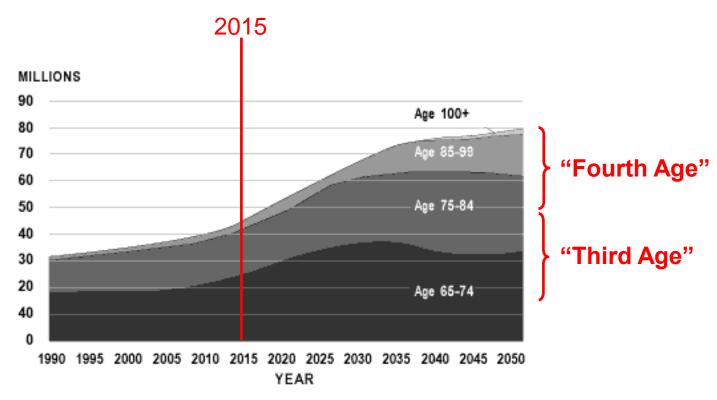


Source: U.S. Census Bureau, Population Projections of the United States by Age, Race, and Hispanic Origin: 1993–2050, P25-1104, 1993

Emergence of the Very Old: Recent Phenomenon



U.S. Population Aging 65 Years and Older: Oldest-Old Fastest Growing Population



Source: U.S. Census Bureau, Population Projections of the United States by Age, Race, and Hispanic Origin: 1993–2050, P25-1104, 1993

Characteristics Third and Fourth Age

"Third Age"

- Active & healthy
- High well-being
- Positive engagement
- Fulfillment of goals
- Generativity

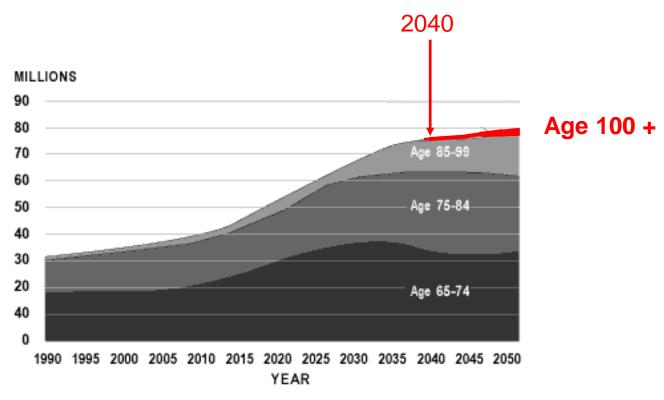
"Fourth Age"

- Chronic diseases
- High vulnerability
- Cognitive restrictions
- Loss of social partners
- Lack of positive things

1990 1995 2000 2005 2010 2015 2020 2025 2030 2035 2040 2045 2050 YEAR

Source: U.S. Census Bureau, Population Projections of the United States by Age, Race, and Hispanic Origin: 1993–2050, P25-1104, 1993

U.S. Population Aging Projections: 800.000 to 1 Million Centenarians in 2040



Source: U.S. Census Bureau, Population Projections of the United States by Age, Race, and Hispanic Origin: 1993–2050, P25-1104, 1993

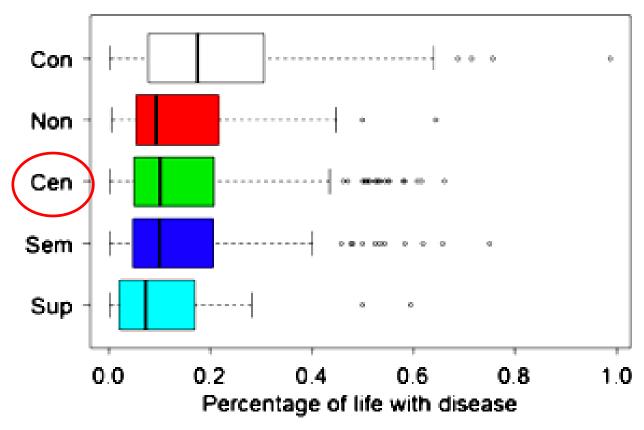
100 Years of Age As Life Perspective

	2000	2001	2002	2003	2004	2005	2006	2007
Canada	102	102	103	103	103	104	104	104
Denmark	99	99	100	100	101	101	101	101
France	102	102	103	103	103	104	104	104
50% of Children Born after Year 2000								
Germany	50	% of	Child	lren F	Born :	after	Year	2000
Germany Italy	50	% of		_				2000
	50	% of		_	Born a			2000
Italy	100	% of		_				103
Italy Japan			Wil	Rea	ch Ag	e 100)!	

Increasing Longevity: Potential Scenarios

- Expansion of morbidity (Ernest Gruenberg, 1977, Morton Kramer, 1980): Increase in life expectancy means more frailty + more morbidity. As a result, more need for care + more burden
- Compression of morbidity (James F. Fries, 1980): Increase in life expectancy goes along with better health. Chronic diseases and disability only happen at the very end of the life span (shortly before death)
- Dynamic equilibrium (Kenneth Manton, 1982): Number of health and disease-dominated years of life remain the same, despite increase in life expectancy. Both increase.

The Older People Get The More Likely They Are to Remain Healthy (?)



Andersen et al., 2012

Different Faces of Reaching 100 Years



100 Years



100 Years

Study the Oldest-Old!

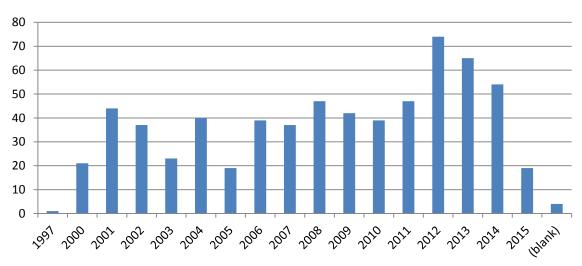
- Fastest growing population in most industrialized nations
- Continuous growth in future
- Recent phenomenon, understudied and underserved population
- Many questions at the individual, family and societal level

Centenarian Research: So Far

Despite rising numbers worldwide, relatively little research

Centenarian Publications 2000-2015

Publications on Centenarians



Centenarian Research: So Far

- Despite rising numbers worldwide, relatively little research
- Most studies focus on demographic development, medical aspects and what may responsible for extreme longevity

Centenarian Research: So Far

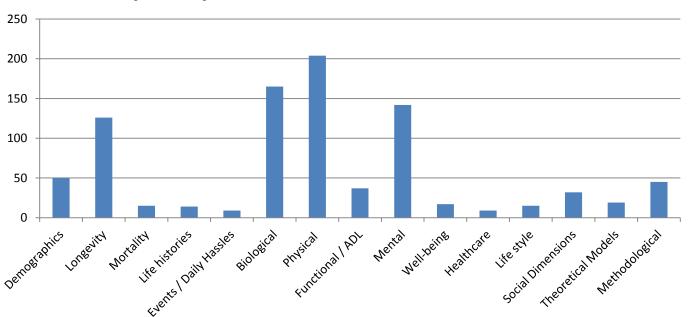
- Despite rising numbers worldwide, relatively little research
- Most studies focus on demographic development, medical aspects and what may responsible for extreme longevity
 - Which means: data assessed via registers (e.g., population registries, mortality data bases) or
 - Biological information (e.g., cell level, disease identification via medical doctor or national data bases)

Centenarian Research: Still Missing

Only few research groups investigate psychological aspects in centenarians

Central Topics In Centenarian Research

Subject Representation in Centenarian Litterature



Centenarian Research: Still Missing

- Only few research groups investigate psychological aspects in centenarians
- Centenarians offer special perspective on psychologial resilience and adaptation given their unique situation

Centenarian Research: Still Missing

- Only few research groups investigate psychological aspects in centenarians
- Centenarians offer special perspective on psychologial resilience and adaptation given their unique situation
 - Which means: need to assess information from centenarian by self-report!

Overarching Goals of Our Studies

- ✓ Allow a differentiated view on very old age
- ✓ Create a more positive and more realistic picture of very old age
- ✓ Determine cultural and societal characteristics involved in shaping life in very old age
- ✓ Identify positive potential for development in old age

24

Our Centenarian Study Network

- Second Heidelberg Centenarian Study (Jopp, PI; completed)
- Fordham Centenarian Study (Jopp, Rott, Boerner & Kruse; completed)
- Oporto Centenarian Study (Ribeiro, Paul; completed)







Findings From the Heidelberg Centenarian Studies

Heidelberg Centenarian Studies: HD100-I and HD100-II

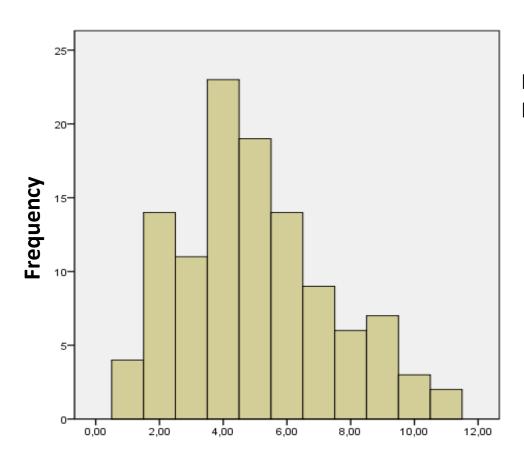
- Population-based samples (N = 91; N = 95)
- All centenarians (i.e., exactly 100 years old) of catchment area invited
- Same 180 registration offices in both studies
- Two birth cohorts: 1900/1901 and 1911/1912
- No exclusion critrion
- Information from centenarian, proxy and interviewer

All Centenarians Have Health Issues...

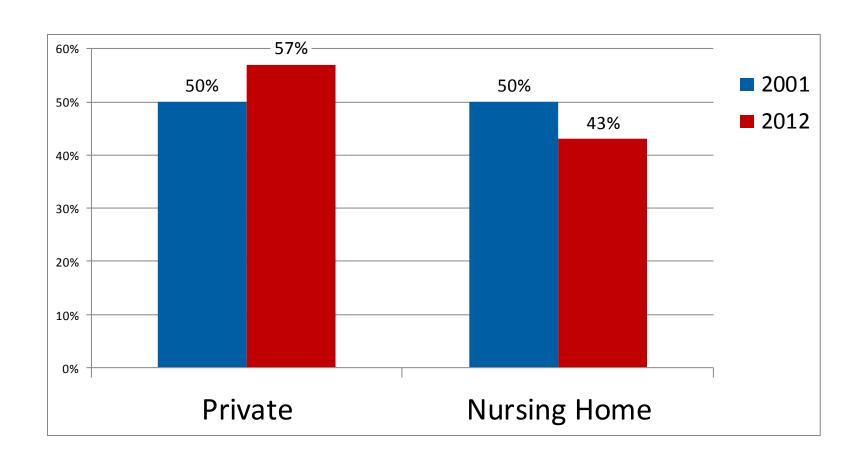
	HD100-II
Vision and/or hearing issues	88%
Falls	67%
High blood pressure	43%
Arthritis	42%
Other health issues	37%
Incontinence	35%
Heart problems	23%
Osteoporosis	21%

Rott, Jopp, et al. (2013)

High Comorbidity: Average of 5 Conditions

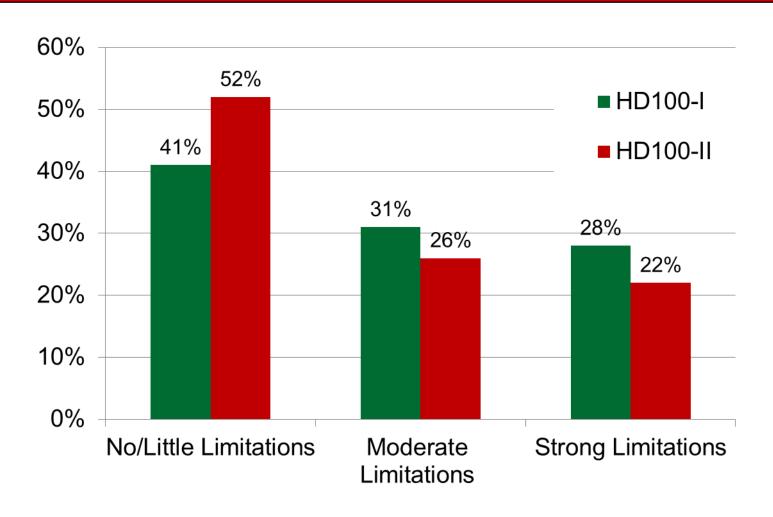


Despite Health Problems: Fewer Centenarians Live in Nursing Homes



Jopp et al. (2013)

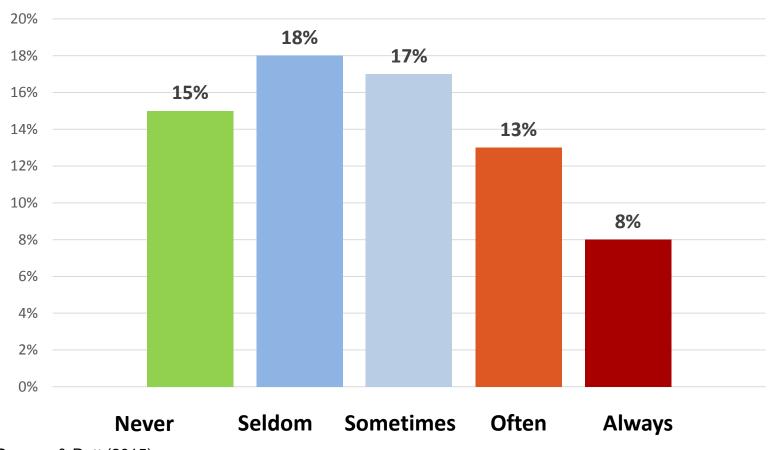
More Centenarians Today Have No or Little Cognitive Limitations



Increased Independence in Physical ADL!

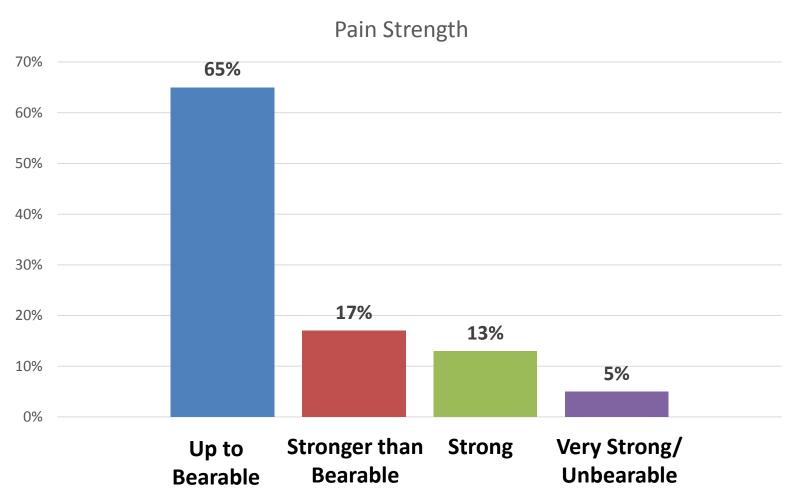
	HD100-I	HD100-II
Eat	61%	83%***
Getting to bathroom on time	41%	44%
Walk	36%	30%
Get in and out of bed	34%	53%*
Take care of own appearance	32%	51%*
Dress and undress	30%	38%
Take a bath or shower	12%	13%

Pain Frequency: Over 20% Often & Always!



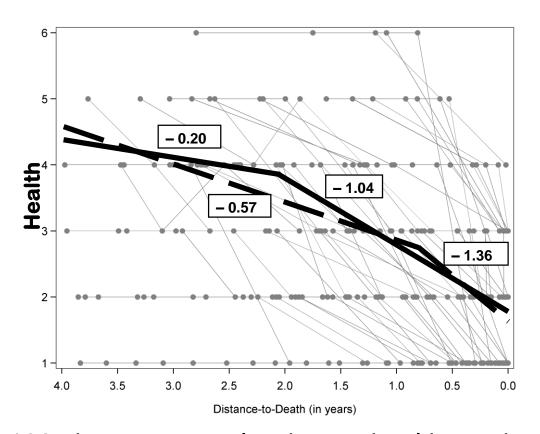
Jopp, Boerner & Rott (2015)

35% Have Pain Levels Exceeding "Bearable"



Jopp, Boerner & Rott (2015)

Health Trajectories Depending on Time of Death

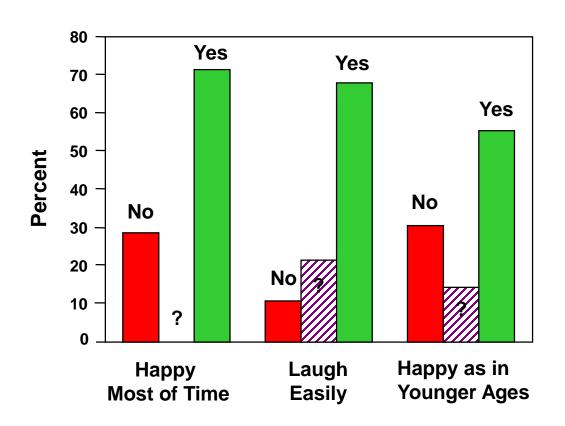


Wozniak et al., 2011

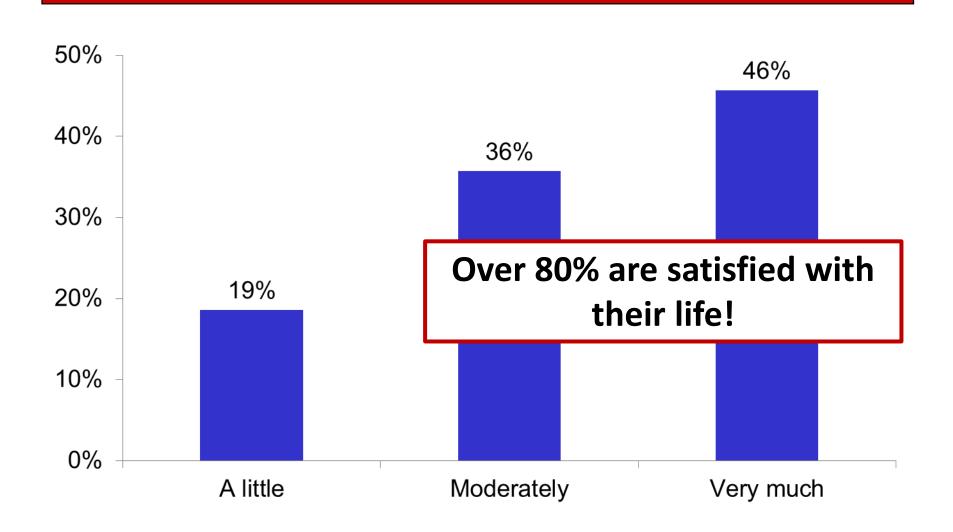
After age 100, there are people who are healthy and stay healthy. For most centenarians, health declines 2.0 and 0.8 years prior to death



Most Centenarian Feel Happy

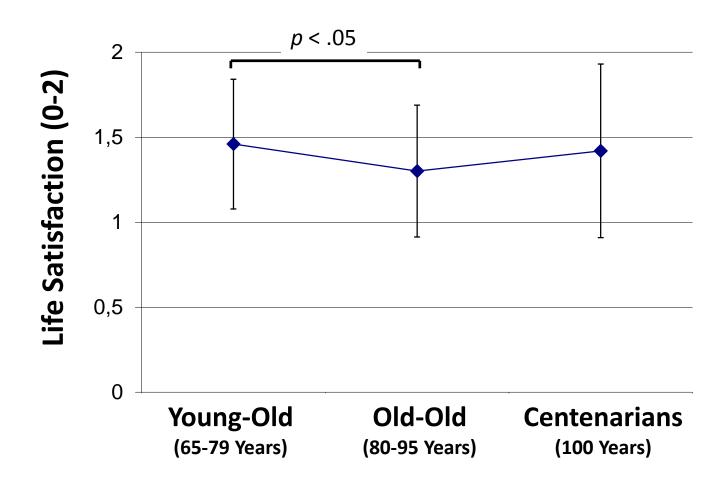


Life Satisfaction in Centenarians



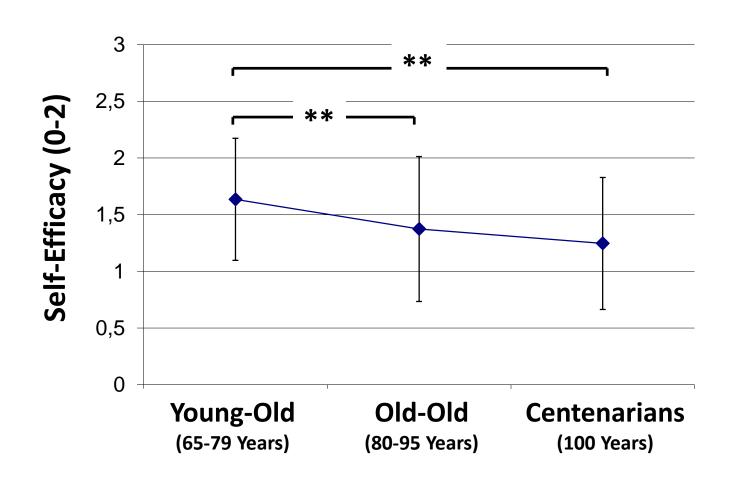
Jopp et al. (2013)

Life Satisfaction: Age Group Comparison



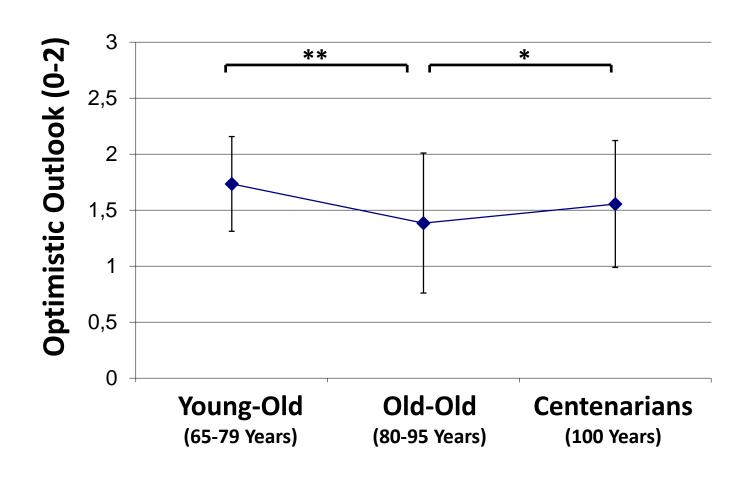
Jopp et al. (2013)

Self-Efficacy: Young-Old Have Higher Levels Than Old-Old and Centenarians



Jopp et al. (2014)

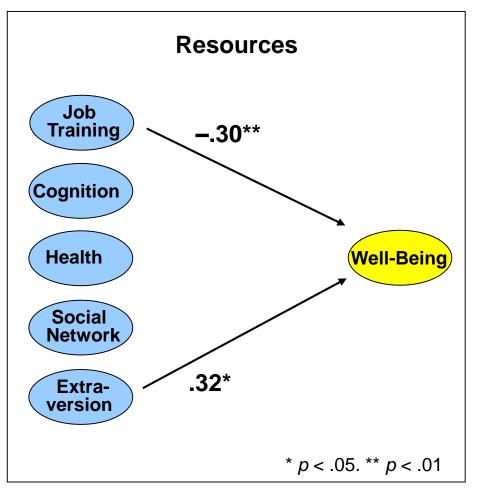
Centenarians Have Higher Optimism Than Old-Old!

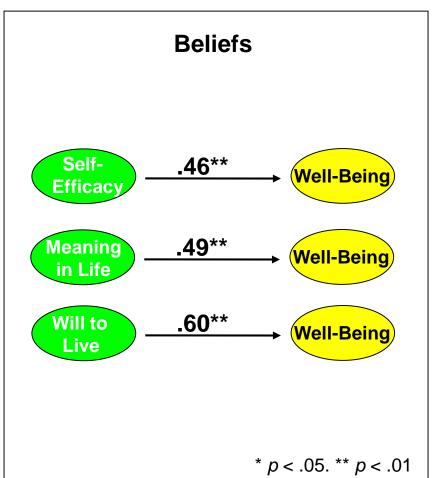


Jopp et al. (2014)

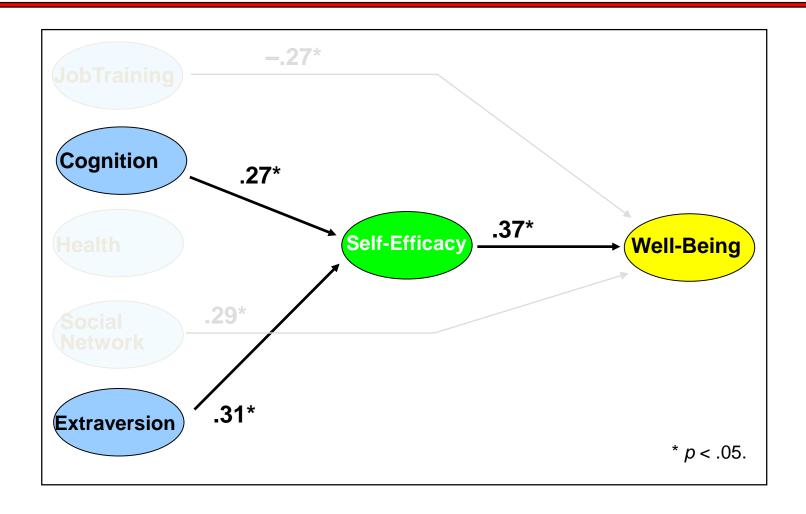
What Predicts Well-Being At Age 100?

Resources: Only Few Direct Effects In Centenarians Beliefs: Strong Effect

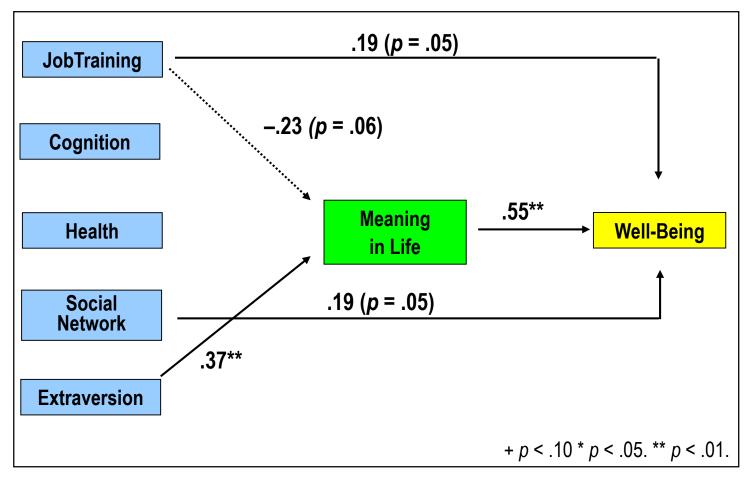




Resources Have Indirect Effects on Well-Being Mediated by Self-Efficacy



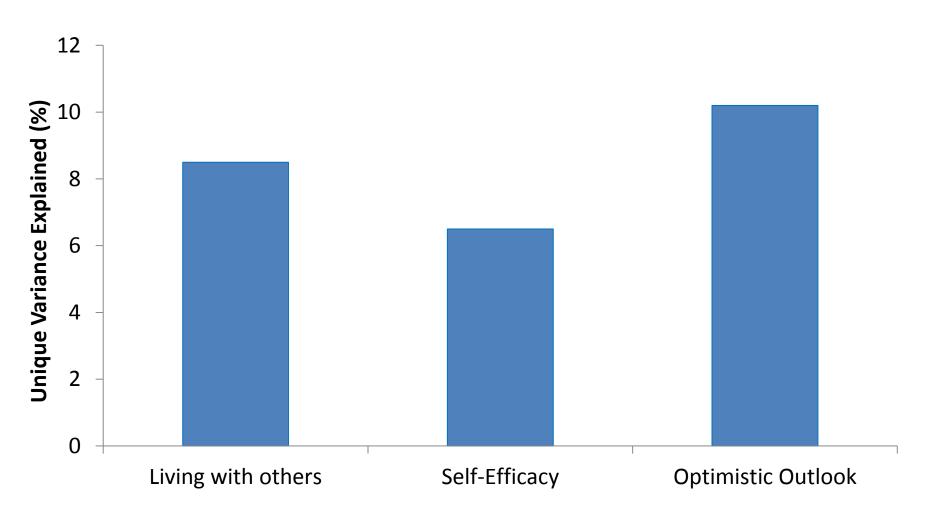
Meaning in Life Mediates Effect of Extraversion



Jopp, Liu, Wozniak, & Rott (2013)

Note. Path Model; Chi2 = 11.38, df = 10, p = .33; RMSEA = .05 (00-.16), GFI = .95, IFI = .97, CFI = .97

Living with Others, Optimistic Outlook and Self-Efficacy Most Important for Life Satisfaction



Jopp et al. (2014)

Promising perspective!!

Findings From the Fordham Centenarian Study

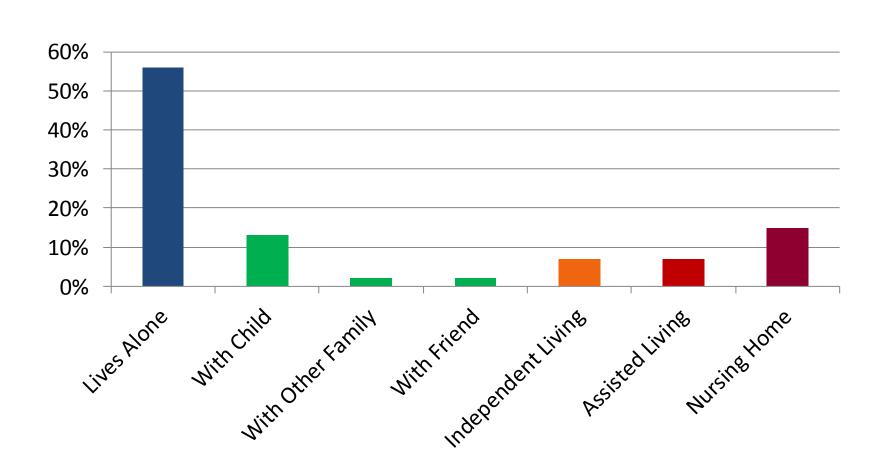
Fordham Centenarian Study

- Funded by Brookdale Foundation Group and Fordham University
- Total of 119 participants
- Average age 99 (95-107 years)
- Recruitment via NYC Voters' Registry
- 79% Caucasian, 19% African-American, 1% Other; 3% Hispanic descent
- 78% women
- 75% widowed; 7% married; 8% divorced/separated; 9% never married
- Rather high education level ($M_{years} = 12.64$)
- Cognitively intact (M_{short MMSE} = 16.48; 21 max possible)

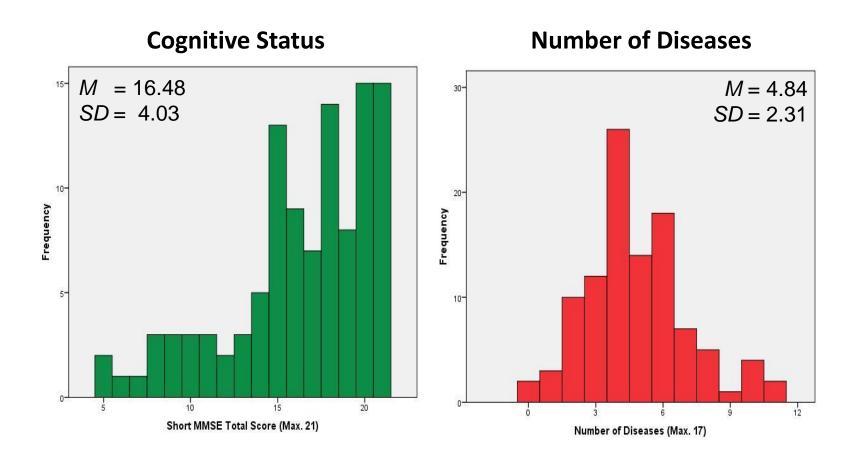
Diverse Cultural Backgrounds



Most Centenarians Live Alone!



Findings: Cognition and Health



⇒ Rather good cognitive status, but challenged physical health

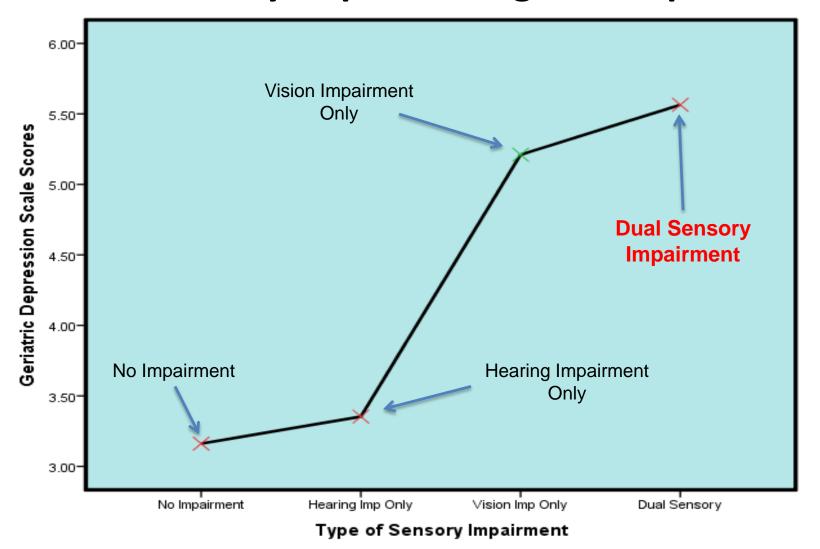
Prevalence of Sensory Impairments: Dual Sensory Impairment is Common

	n	%		
Self-rated Vision Impairment				
Poor	32	27.4		
Fair	32	27.4		
Good	31	26.5		
Very good	15	12.8		
Excellent	7	6.0		
Self-rated Hearing Impairment				
Poor	17	14.5		
Fair	48	41.0		
Good	36	30.8		
Very good	13	11.1		
Excellent	3	2.6		
Sensory Impairment Status				
No impairment	32	27.4		
Vision impairment only	20	17.1		
Hearing impairment only	21	17.9		
Dual sensory impairment	44	37.6		

How do Centenarians Compare to Younger Ages (65-94 years)?

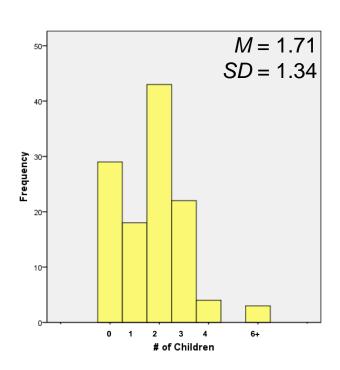
- Sensory impairment free was less common (27% vs. 40%)
- Dual sensory impairment was higher (40% vs. 20%)
- Hearing impairment only was less common (16% vs. 22%)
- Vision impairment rates are similar (about 20%)

Dual Sensory Impaired: Highest Depression

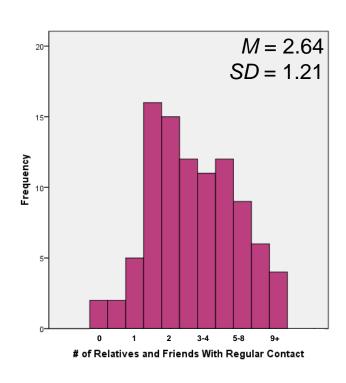


Social Resources

Children

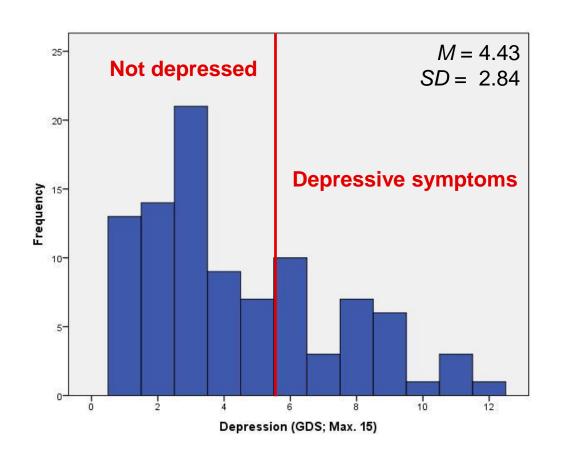


Social Partner



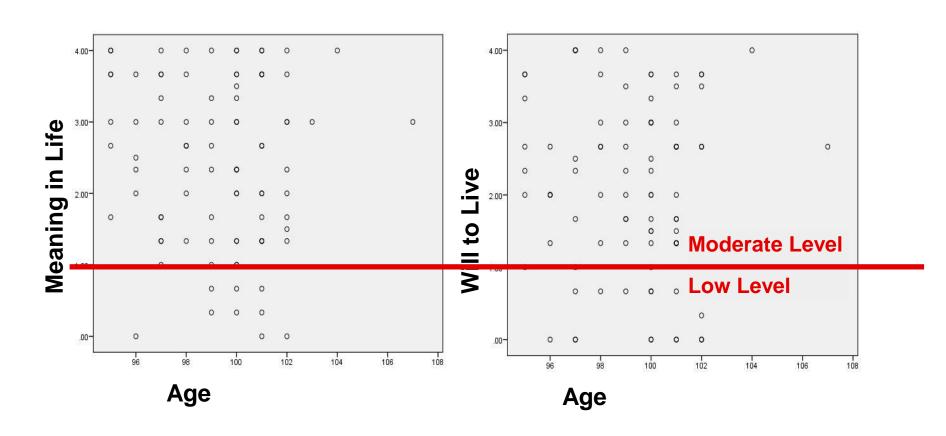
⇒ Social resources: so-so...

Centenarians Are Not Depressed



 \Rightarrow Most show no signs of depressive mood

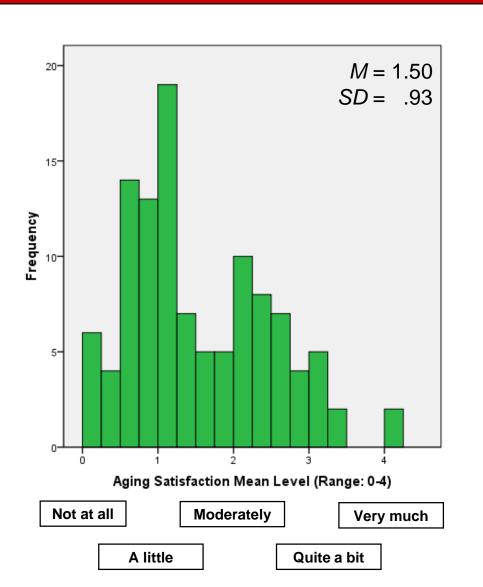
Psychological Strengths: Meaning in Life & Will to Live



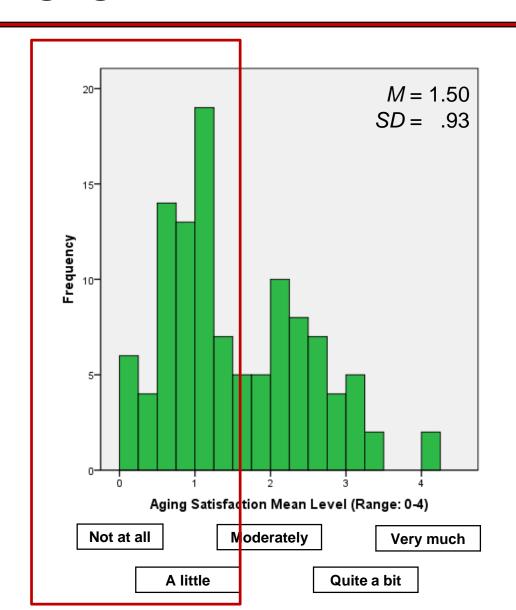
⇒ Strength levels rather high, but show variation

What Allows Centenarians To Be Satisfied With Their Age?

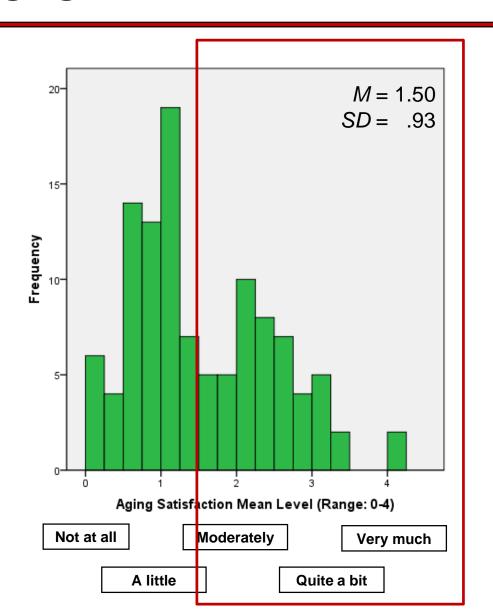
Aging Satisfaction: Mean Levels



Aging Satisfaction: Mean Levels



Aging Satisfaction: Mean Levels



Finances and Health Important for Aging Satisfaction

Aging Satisfaction

Sociodemographic resources			
Age, gender, education, married, pay bills	all ns		
Difficulty to pay medication	30**		
Health resources			
Cognitive status	21*		
Subjective health	.28**		
Subjective vision	.44**		
Subjective hearing	.37**		
IADL	31**		
ADL	34**		
Number of disease	30**		
Health restrictions	36**		

Note. * p < .05. ** p < .01.

Social Resources Less Important for Aging Satisfaction

	Aging Satisfaction	
Social resources		
Number of children	.14	
Number of visits	.07	
Frequency time spent with others	.02	
Family seen as often as wanted	.27*	
Confidants	.21+	
SOS contacts	.23*	

Note. + p < .10. * p < .05. ** p < .01.

Personality, Beliefs and Strategy More Important

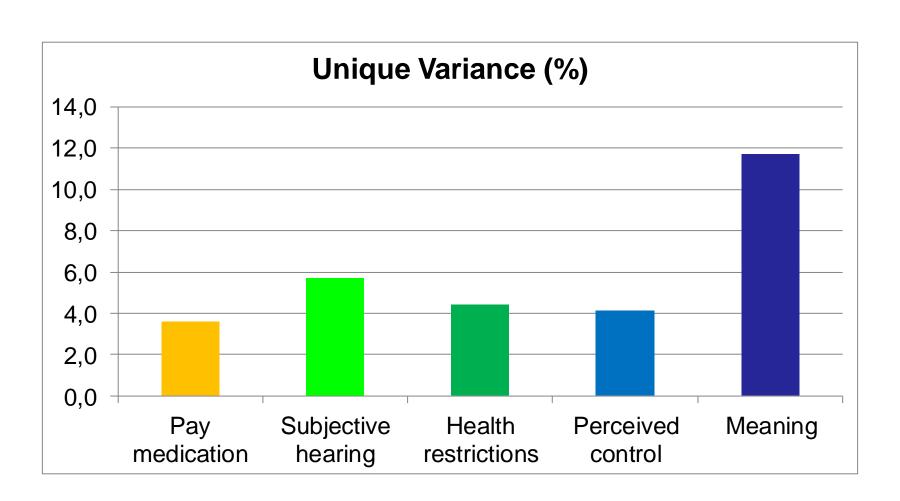
	Aging Satisfaction	
Personality		
Extraversion	.30**	
Conscientiousness	.17	
Neuroticism	18	
Beliefs		
Perceived control	.30**	
Self-efficacy	.27*	
Positive outlook	.39**	
Meaning in life	.54**	
Will to live	.37**	
Coping		
Proactive coping	.23*	
Other strategies	ns	

Combined Regression Model

	β	R^2_{TOT}	
Combined Model		.52**	
Difficulty to pay medication	21*		
Subjective vision	.05		
Subjective hearing	.26*		
Health restrictions	19, $p = .07$		
Family seen as often as wanted	.05		
Extraversion	.03		
Perceived control	.15, p =	.14	
Meaning in life	.32*		
Proactive coping	.09		

Note. * *p* < .05. ** *p* < .01.

Meaning in Life is Most Important For Aging Satisfaction



Summary I

- Centenarians in both Germany and USA have rather high resources, but are challenged by health issues.
- Most centenarians are not depressed and value their lives.
- Centenarians are active and future oriented.
- Centenarians have high levels of psychological strengths.
- Resources play less of a role for aging satisfaction than expected, but psychological aspects very important.

Summary II

- Centenarians of more recent cohorts seem healthier and better cognitive intact.
- Increasing number of centenarians does not result in more individuals with more severe limitations!
- Similar finding in other countries (e.g., Denmark) indicate global trend.
- More complex analysis needed to determine psychological mechanisms for well-being.

Part II: Issues in Centenarian Research

Centenarian Research: Potential Complications

Any thoughts?

Centenarian Research: Complications

- Ethical considerations
 - Highly vulnerable group
 - Can be difficult and timely to get IRB approval
- Recruitment
 - Population-based
 - Volunteers
 - Sample selectivity
 - Access to specific subgroups (e.g., nursing home residents)
- Design
 - Usually cross-sectional
 - Prospective studies: only few may reach 100
 - Longitudinal studies difficult due to participant burden

Centenarian Research: Complications

- Missing comparison group
 - Centenarians are survivors, thus highly selected
- Assessment challenges
 - In-person
 - Adjustment of measures
 - Person-centered assessment
 - Intense interviwer training needed
- Data properties
 - Small samples
 - Biased distributions, non-normal

What Do We Know About Centenarians?

 And how should this translate in our research efforts?

Special Attitude and Attention Needed

- Centenarian share very special moments
 - Are per definition close to their end of life, have limited time left
 - Are valuable source of information, but may not "function" as do other study participants
 - Need more patience, different study approach
 - May share info in different places across interview, need for flexibility on interviewer end
 - Need to develop sensitivity for exhausion (physical, emotional)
 - Adjustment of schedule/interview based on capacity
 - Competence/concentration may vary from time to time (shortterm variation)

Difficult to Find Enough Centenarians...

- Use statistical means to deal with small sample sizes and non-normal distribution
- Increase sample size to conduct more powerful analysis by:
 - Compare cohorts of centenarians assessed with same measures
 - Combine data sources (International Centenarian Consortium)
 - Create network of parallel studies with shared goals and measures

Important Step: Determine Cognitive Capacity

- Widely used: Mini-Mental State Examination (Folstein et al.)
- Group work:
 - Please have a close look at measure individually
 - Role play: assess MMSE with partner pretending being 100
 - Discuss what could be problematic for a centenarian

Issues MMSE

- Sensory load of items
 - Vision, hearing problems
 - Issues with drawing, bending
 - Lack of age fairness (not considering above health issues)
- Proposal by Holtsberg et al. (1995) to reduce scale to those with low sensory load (Shortened MMSE, max 21 points)

Information Sources

Centenarian

- Self-report
- Potential cognitive (e.g., dementia) and health (e.g., sensory, overall energy) issues

Proxy respondent

- Answers questions about centenarian
- Info is as good as knowledge about the centenarian
- May have biased view or
- Objective vs subjective information
- Observer (e.g., interviewer)
 - Standard measues (e.g., Global Deterioration Scale)

HD100 Health Data

- Centenarian
- Proxy respondent
- Observer (e.g., interviewer)

Health: Comparison Reports From Centenarians and Proxies

	Centenarian	Proxy
Global health		
Actual	1.74	1.83
Compared to earlier	.91	.66
Hinders activities	1.27	1.32
Functional health		
Mobility limitations	.65	.77*
ADL	10.55	9.19***
IADL	5.79	4.68*
Sensory issues		
Issues talking on phone	1.53	1.73+
Issues in conversations	1.64	1.72

⁺ p < .05. * p < .05. *** p < .001.

Predicting Health From Different Sources

	Centenarian	Proxy	Interviewer
Cognitive status	11	13	07
ADL	10	.43**	.38**
Sensory issues			
Vision problems	.00	18	19
Hearing problems	01	12	18
Psych health	.63***	.27**	.32**
Corrected R ²	.30	.38	.56

Preference of Information Sources

Centenarian

- Self-report for well-being, emotions, psychological constructs such as personality
- Preference for centenarian for all subjective measures

Proxy respondent

- Objective aspects (e.g., profession, formal help, ADL/IADL if involved, number of children)
- Preference for proxy
- Some researchers also assess personality
- Health indicators show differences to centenarian, depends on area

Observer (e.g., interviewer)

- Always good to have
- Training very important

Well-Being and Other Self-Report

- Different approaches
 - Standard questionnaire (e.g., Life satisfaction, Pavot & Diener)

Life Satisfaction

• Original items:

	1 = strongly disagree	2 = disagree	3 = slightly disagree		7 = strongly agree
1. In most ways my life is close to my ideal.	0	1	2		7
2. The conditions of my life are excellent.	0	1	2		7
3. I am satisfied with my life?	0	1	2		7
4. So far I have gotten the important things I wanted in life.	0	1	2		7
5. If I could live my life over, I would change almost nothing.	0	1	2	•••	7

Well-Being and Other Self-Report

- Different approaches
 - Standard questionnaire (e.g., Life satisfaction, Pavot & Diener)
 - Number of items
 - Complexity of formulation
 - Number of answering options
 - High cognitive load

Well-Being and Other Self-Report

Different approaches

- Standard questionnaire (e.g., Life satisfaction, Pavot & Diener)
 - Number of items
 - Complexity of formulations (e.g., double negations)
 - High cognitive load
 - Reformulation of statements into questions
 - Adjustment/reduction of answering formats
 - Unfolding to support answering
 - Visual support for answering format

Life Satisfaction

• Changed items:

	0 = not at all	1 = a little	2 = mode- rately	3 = quite a bit	4 = very much
1. In most ways, is your life close to your ideal?	0	1	2	3	4
2. Do you think that the conditions of your life are excellent?	0	1	2	3	4
3. Are you satisfied with your life?	0	1	2	3	4
4. So far, did you get the most important things you wanted in life?	0	1	2	3	4
5. If you could live your life over, would you change anything?	0	1	2	3	4

Well-Being and Other Self-Report

- Different approaches
 - Standard questionnaire (e.g., Life satisfaction, Pavot & Diener)
 - Number of items
 - Complexity of formulation
 - Number of answering options
 - High cognitive load
 - Open-ended questions
 - Structured, semi-structured, open
 - Training of interviewers
 - Coding of material
 - (non-reactive measures; facial coding etc)

Coding of Open Reports: Centenarians Are Active

Regular activities:

- Visit museums, attend lectures
- Read newspaper daily
- Volunteer at schools and churches
- Travel
- Exercise and practice yoga
- Sew and knit





Centenarians Have Goals

- Fordham: 84% reported goals they pursue
 - Areas most mentioned: health, family, friends, and leisure
 - Examples:

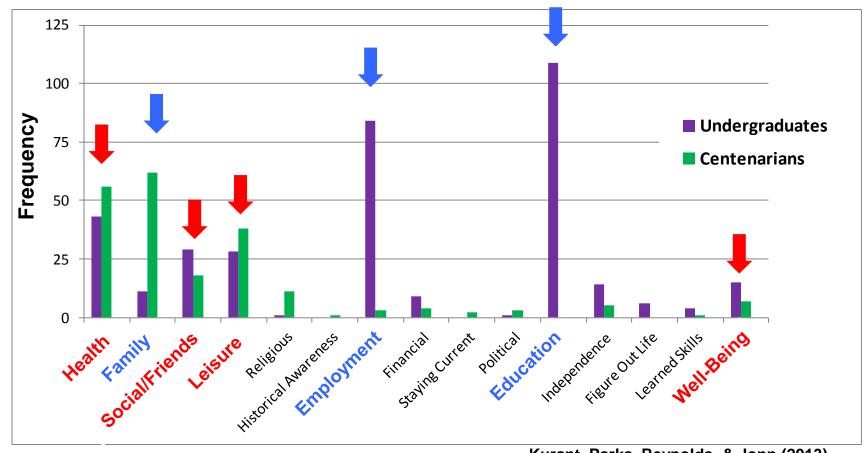
```
"To be happy and make others happy."
```

"Get up everyday and visit neighborhood friends."

"I want to watch my family succeed."

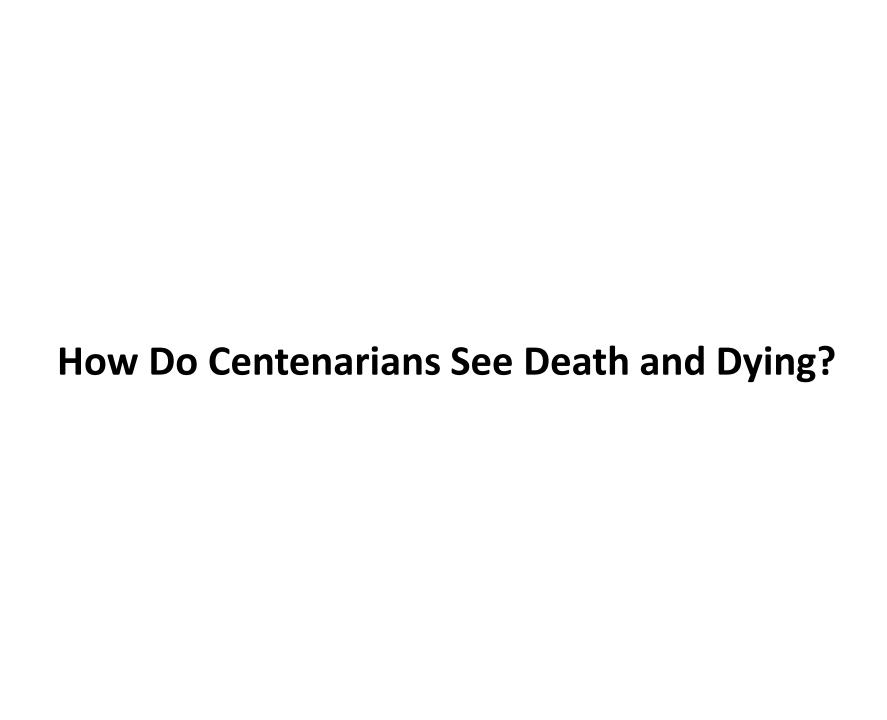
"Have curiosity to learn new things."

And Their Goals Do Not Differ Much From Yours... Expected Differences and Unexpected Similarities Undergraduate Students vs Centenarians



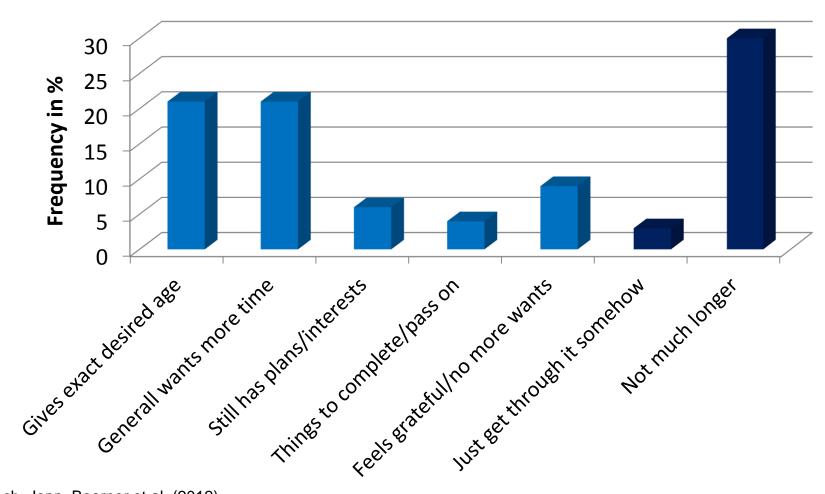
Interview Design

- How to Select Content (i.e., what to ask and what not?) and in Which Sequence?
- Besides the things we really want to assess for theoretical etc purposes, what should be added to the interview to increase responsiveness and enjoyment of the study?
- How can we mix standard questionnaires with open interview parts and tests to keep people going?
- Can we ask centenarians about death and dying given their closeness to death?



Desired Age of Centenarians: Responses Reflect Future Orientation

What age would you like to reach?



What's Behind Wanting More Time (Or Not)?

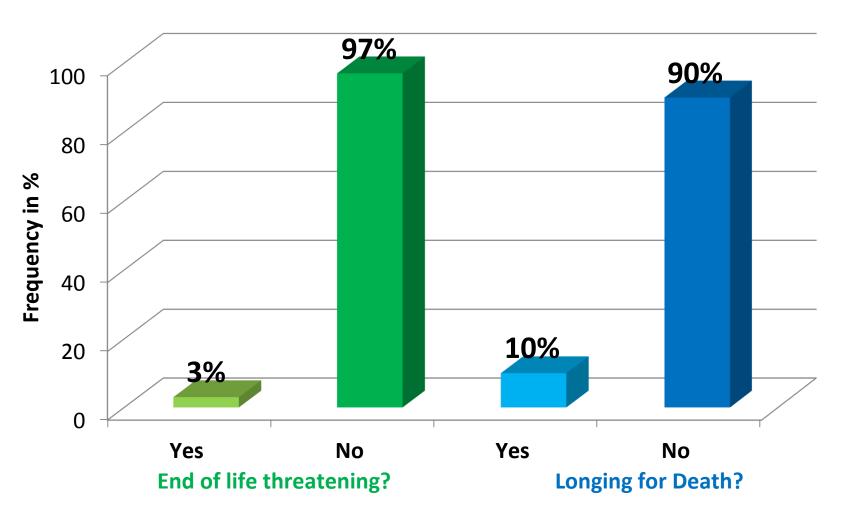
More time

- Ability focus
 - Physical fit
 - Basic ADLs
 - Ability to experience
 - Ability to converse
- Acceptance
 - Death part of life

No more time

- Loss focus
 - Loss of health
 - Loss of social life
 - Vulnerability
- Negative life conditions
 - Poor care conditions

End of Life Not Threatening & No Longing for Death



Summary

- Multiple challenges in centenarian research, but doable
- Offers very interesting insights on important questions
- Allows access to centenarians' knowlegde of value to our society
- Will help to address challenge of global aging

Thanks Goes To

- Robert Bosch Foundation
- Dietmar Hopp Foundation
- Brookdale Foundation Group
- Fordham University
- All our study participants and their families
- My teams at Institute of Gerontology, Heidelberg, and Fordham Adult Development and Aging Lab

Fordham Centenarian Study Team





























Heidelberg Centenarian Study Team

























