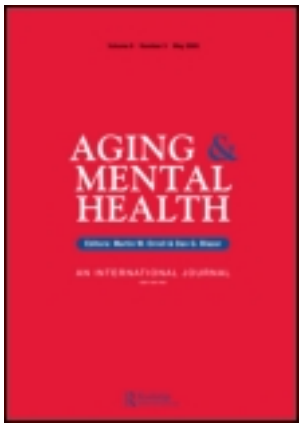

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Experience of aging in patients with rheumatic disease: A comparison with the general population

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Objectives: Self-perceptions of aging have been shown to predict mental and physical health and even longevity. This study examined the aging perceptions of patients with rheumatic disease and compared them with the general Dutch population.
Methods: Consecutive patients visiting a rheumatology clinic completed the Personal Experience of Aging Scale (PEAS) subscales: physical decline, social loss, continuous growth, and two sentence stems from the SELE instrument (What I like/do not like about getting older . . .) as qualitative measures of the subjective experience of aging. A representative sample from the general Dutch population between 40 and 85 years was used as a comparison group. Participants included in this study were 208 patients with a rheumatic disease and 975 persons from the Dutch Aging Survey (DAS).
Results: Both quantitative and qualitative data showed that patients perceived aging more strongly as physical decline. These negative experiences did not extend to social and psychological domains of aging. Age-group comparisons revealed that patients in middle adulthood experienced physical aging similar to older people without a rheumatic disease.
Conclusion: The negative experience of aging in patients is limited to the physical domain and does not extend to other domains of life. The negative experience of physical aging even in middle-aged groups warrants further studies on its effects on mental and physical health outcomes and health behavior in patients with rheumatic disease.

Keywords: arthritis; self-perceptions of aging; attitudes toward aging; older patients; general population

Introduction

Research provides evidence that the personal experience of aging plays an important role in the health, well-being, and quality of life of older persons (Levy, 2003). The experience of aging refers to self-perceptions of the individual's own aging process. These perceptions are multidirectional and multidimensional, implying that individuals experience both gains and losses in different domains, such as physical, psychological, and social functioning (Steverink, Westerhof, Bode, & Dittmann-Kohli, 2001; Westerhof, Whitbourne, & Freeman, 2011). Studies of the general population have shown that positive self-perceptions of aging were positively related to physical functioning and to the absence of depression (Barker, O'Hanlon, McGee, Hickey, & Conroy, 2007) and higher levels of well-being (Steverink et al., 2001; Westerhof, 2003). These positive attitudes toward aging longitudinally predicted preventive health behaviors (Levy & Myers, 2004), such as physical exercise in older adults (Wurm, Tomasik, & Tesch-Römer, 2010), positive physical health outcomes (Levy, Slade, & Kasl, 2002; Wurm, Tesch-Römer, & Tomasik, 2007), and even longevity (Levy, Slade, Kasl, & Kunkel, 2002). All cited effects remained statistically significant after controlling for obvious criteria that might have influenced the association between the experience of aging and the outcome variables (e.g., chronological age, health status, subjective health, loneliness, sex, marital status, SES). It has also repeatedly been reported that attitudes toward one's own aging are associated with health outcomes and physical functioning in patient populations. Individuals' belief about their own aging predicted the likelihood of dying from respiratory causes in patients with chronic obstructive pulmonary disease (Levy & Meyers, 2005), were associated with the acquisition of support in multiple sclerosis (Harrison, Blozis, & Stuifbergen, 2008), and physical recovery after acute myocardial infarction (Levy, Slade, May, & Caracciolo, 2006).

In rheumatology, similar concepts are discussed with regard to osteoarthritis (OA). Patients with OA often experience symptoms such as pain, stiffness, and difficulties in daily functioning (e.g., walking or climbing stairs) as a result of the wear and tear of normal aging and not as signs of a disease that has to be treated. In line with this, general practitioners judged the disease as clearly more serious than the patients themselves (Heijmans, Foets, Rijken, Schreurs, & de Ridder, 2001). Turner, Barlow, Buszewicz, Atkinson, and Rait (2007) suggested that patients who consider their disease to be part of normal aging were more reluctant to seek medical help

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and tended to refrain from medical and paramedical help. Various studies supported this relationship (Appelt, Burant, Siminoff, Kwoh, & Ibrahim, 2007; Ballantyne, Gignac, & Hawker, 2007; Gignac et al., 2006; Sarkisian, Hays, & Mangione, 2002; Sarkisian, Lee-Henderson, & Mangione, 2003). Disease symptoms and self-perceptions of aging in the physical domain might mutually reinforce one another, eventually resulting in a negative cycle of further physical decline (PD) and mental health problems like elevated levels of depressive mood.

The studies described above illustrate that self-perceptions of aging might have serious consequences for the treatment of OA patients and the course of their illness. However, most results came from qualitative studies with small samples of OA patients and without comparison groups. No studies have investigated the experience of aging in other rheumatic diseases. The innovative objective of this study was to examine the experience of aging systematically in a population with various rheumatic diseases and to compare the findings with the results in a general population. Until now, it was unclear, whether other dimensions of aging are also affected by negative views of physical aging. Due to the impact of arthritis on psychological and social functioning (Geenen, Mulligan, Shipley, & Newman, 2009), we reasonably expected less positive perceptions in these domains too. Furthermore, age differences in perceptions of aging in patients and the general population were examined, as we expected smaller age-group differences in patients.

The following associations were hypothesized:

(1) Due to the consequences of a rheumatic disease for physical functioning, patients would have more negative self-perceptions of aging with regard to the physical domain than the general population.
(2) Due to the impact of limitations, we expected that the experience of aging in other domains would also be less positive for patients with rheumatic disease in comparison to the general population of comparable age.
(3) Since the experience of aging refers to self-perceptions of the individual's own aging process, we expected less positive experiences in older than in middle-aged persons. However, the impact of limitations caused by arthritis might result in smaller age-group differences in patients with rheumatic disease compared to the general population.

Methods

Procedure

Consecutive patients between 40 and 85 years, who visited the outpatient clinic for rheumatology of Medisch Spectrum Twente (NL) were invited to participate in this study. Participants filled out a paper and pencil questionnaire. Provided with written information, patients then gave their consent for participation. A sample of 975 adults, aged 40–85 years old who were living independently participated in the Dutch Aging Survey (DAS; Westerhof, 2003). The DAS involved a stratified random sample of persons drawn from cities, towns, and rural communities in the Netherlands. The sample was stratified by sex and age-group (ages 40–54, 55–69, and 70–85).

Participants' characteristics and dropout

At the outpatient rheumatology clinic, 208 of the invited 271 patients were willing to participate (76.8%). Reasons for refusal were feeling too ill and not being motivated to participate. The response rate for the DAS was 44.1%. Older adults declined more often because of illness or disability. The final sample thus contained an overrepresentation of healthy people between the ages of 70 and 85. Table 1 presents the characteristics of the participants of both samples. No differences between the samples were found in mean age and marital status. Participants in the patient sample were more often female, had less education, were more often disabled, and less often housekeepers than participants in the population sample. In the patient sample, 52% were diagnosed with rheumatoid arthritis, psoriatic arthritis, and other arthritides, 10.6% with gout, 6.1% with osteoarthritis, and 31.3% had other rheumatic diseases. The mean disease duration was 8.6 years (SD = 10.1). Patients reported a mean pain score of 4.8 (2.7) on a numeric scale (0 = no pain, 11 = unbearable pain) for the last week and a mean score of 0.7 (0.66) on the HAQ-DI (range 0–3, no disability – severe disability; Bruce & Fries, 2003). Mental and physical well-being were measured with the SF36 (Ware, Kosinski, & Keller, 1994) and resulted in mean scores of 37.8 (9.0) for physical well-being and 48.8 (10.5) for mental well-being. (A mean score of 50 represents the general population, lower scores indicate worth well-being.) In the DAS, 50.6% of the participants indicated 'back and joint symptoms' on a self-report symptom list, where 8.5% of them reported no complaints, 38.1% few complaints, 27.2% mild complaints, and 26.0% many complaints caused by these symptoms.

Instruments

Two sentence stems deriving from the SELE-sentence completion questionnaire (Westerhof, 2003) were used as a qualitative measure of the subjective experience of aging: 'What I like about getting older . . .' and 'What I don't like about getting older . . .' The sentence completions were coded using a coding scheme (Westerhof, 2003) with a high intercoder reliability (Cohen's kappa of 0.92 for the DAS sample [between coders Bode and Westerhof] and 0.91 for the patient data [between

Table 1. Demographics for the patient sample and the DAS.

	DAS ($n = 975$)	Patient sample ($n = 208$)	χ^2 (df)	t (df)	p
Age in years (mean, SD)	60.8	62.1		−1.28 (1143)	0.20
Women (in %)	50.4	58.2	4.3 (1)		0.04
Education (*in* %)			14.7 (2)		0.001
Maximum 6 years	19.1	24.1			
7–13 years	56.6	64.7			
More than 13 years	24.3	11.2			
Work status (*in* %)			45.3 (7)		<0.001
Employed	32.4	30.0			
(Pre-)retirement	32.1	37.6			
Housekeeping	25.8	16.5			
Disabled	7.3	14.1			
Unemployed	2.3	1.8			
In education	0.1	0			
Marital status (*in* %)			1.8 (3)		0.61
With partner	76.4	77.1			
Without partner	5.3	2.9			
Widowed	13.4	14.7			
Divorced	4.9	5.3			

coders Bode and van Gessel]) The coding scheme consists of six codes, referring to the physical domain (e.g., 'bodily decline' and 'the medication allows me to be physically active again'), the social domain (e.g., 'the loss of friends' and 'a grandson is born'), the psychological domain (e.g., 'forgetfulness' and 'more life experience'), negations (e.g., 'nothing'), general statements (e.g., 'everything'), and 'don't know' answers (e.g., 'I have no idea').

The Personal Experience of Aging Scale (PEAS; Steverink et al., 2001; Westerhof, 2003) was used to measure self-perceptions of aging as: (1) physical decline (PD), (2) social loss (SL), and (3) continued growth (CG). Each subscale consisted of four items (e.g., 'Aging means to me that I have less physical endurance'.), which respondents answered on a four-point scale (totally agree – totally disagree). The reliability coefficients (Cronbach's alpha) for the DAS sample were good (PD: 0.78, SL: 0.72, CG: 0.70). In the patient sample, the reliability was comparable, except for one subscale (PD: 0.60, SL: 0.79, CG: 0.68). Sum scores were computed for each subscale with higher scores indicating stronger perceptions of aging as PD, SL, and CG (range of scores varied between 0 and 12).

Statistical analyses

For the comparison of the samples, differences in demographics between the samples were analyzed with t-tests and χ^2-tests. To test our three hypotheses in the sentence completion data, differences between the two samples and between the age groups were analyzed with χ^2-tests. Adjusted standardized residuals were used to detect the location of the differences in the cross-table. Differences between cells were assumed to be significantly different when standardized adjusted residuals were < -2 or > 2 (Everitt, 1992).

Since the data of the subscales of the PEAS were not normally distributed, nonparametric tests were used to test the three hypotheses in the questionnaire data. Differences between the two samples were analyzed with the Mann-Whitney test and that between three age-groups within each sample were examined with the Kruskall-Wallis test.

Results

Results of the sentence completions

The sentence 'What I *do not like* about getting older...' asked for self-perceptions of age-related losses. Patients with rheumatic disease gave significantly different answers in comparison to participants from the DAS ($\chi^2(1097, 5) = 39.15$; $p < 0.001$). The patients focused more often on physical losses, whereas subjects from the general population mentioned social and psychological drawbacks more often (Table 2). There were no age differences in sentence completion in both samples (DAS: $\chi^2(907, 10) = 13.9$; $p = 0.23$; patients: $\chi^2(146, 6) = 4.9$; $p = 0.55$; data not shown).

How participants completed the sentence 'What I *like* about getting older...' did not differ between the two samples ($\chi^2(1073, 5) = 7.9$; $p = 0.16$, Table 2), but both samples showed age differences (DAS: $\chi^2(898, 10) = 109.9$; $p < 0.001$; patients: $\chi^2(131, 10) = 45.3$; $p < 0.001$, Table 3). The younger age group (40–54 years) reported clearly more often advantages in the psychological domain, whereas the older groups (55–65 and 66–85 years) described the benefits of getting older significantly more often in the social domain. These differences were in the same direction for both samples, but more pronounced in the patient

Table 2. Sentence completions for DAS and patient sample in percentages.

	DAS	Patients
What I do not like about getting older . . .[a]		
Physical domain	55.6*	79.5*
Social domain	16.9*	6.8*
Psychological domain	4.9*	0*
Negation	7.9	7.5
General	6.8	6.2
Don't know	7.8*	0*
What I like about getting older . . .[b]		
Physical domain	1.9	5.3
Social domain	48.9	50.4
Psychological domain	28.6	23.7
Negation	7.5	9.2
General	7.4	7.6
Don't know	5.6	3.8

Notes: [a]$\chi^2(1097, 5) = 39.15$; $p < 0.001$.
[b]$\chi^2(1073, 5) = 7.9$; $p = 0.16$.
*Standardized adjusted residuals: < -2 or > 2.

Table 3. Sentence completions for the sentence 'What I like about getting older. . .' for age groups in percentages.

DAS[a]	40–54 years ($n = 338$)	55–65 years ($n = 209$)	66–85 years ($n = 351$)
Physical domain	0.9	1.0	3.1
Social domain	34.0*	57.4*	58.1*
Psychological domain	47.3*	22.5*	14.2*
Negation	5.0*	10.0	8.5
General	7.4	4.8	9.4
Don't know	5.3	4.3	6.6
Patients[b]	**40–54 years ($n = 35$)**	**55–65 years ($n = 40$)**	**66–85 years ($n = 56$)**
Physical domain	2.9	0	10.7*
Social domain	20.0*	45.0	73.2*
Psychological domain	42.9*	35.0*	3.6*
Negation	11.4	7.5	8.9
General	11.4	10.0	3.6
Don't know	11.4*	2.5	0*

Notes: [a]$\chi^2(898, 10) = 109.9$; $p < 0.001$.
[b]$\chi^2(131, 10) = 45.3$; $p < 0.001$.
*Standardized adjusted residuals: < -2 or > 2.

sample (Table 3). These results confirmed hypothesis 1 that patients have more negative self-perceptions of aging regarding physical issues, but disconfirmed hypothesis 2 that these extend to other aspects of the experience of aging. Age-group differences were only found in the positive sentence completions. Hypothesis 3 was only partly confirmed.

Results of the PEAS

Patients with rheumatic disease associated their aging process significantly stronger with physical loss than participants from the DAS (Table 4). This result supported our first hypothesis. Self-perceptions of aging regarding SL and CG did not differ between the samples. Again, negative experiences with physical aspects did not extend to other domains (contrary to hypothesis 2).

When analyzing the differences of experiences of aging between the three age-groups, significant differences for all subscales were found in the DAS sample (Table 4). Older participants reported more PD (55 years and older), more SL (55 years and older), and less CG (66–85 years). In the patient sample, the oldest group (66–85 years) also experienced most SLs and least CG. However, no age-group differences were found for PD among patients between 40 and 85 years of age. Patients with rheumatic disease of different ages experienced aging to a similar degree as PD. These results partially confirmed our hypotheses. Only in the domain of physical loss did we find different patterns for patients and individuals from the general population.

Discussion

This study investigated how patients with rheumatic disease experienced the aging process in comparison to individuals from the general population. Results of the quantitative and qualitative measures revealed that patients indeed perceived their aging process more strongly as PD, which supports hypothesis 1. SL was reported as an aspect of one's own aging to the same degree in both samples. Positive connotations of aging did not differ between the two samples under investigation as well. An important finding of this study was that, contrary to hypothesis 2, the negative experiences of the patients in the physical domain did not extend to other domains of life. Age-group analyses supported this finding and uncovered another aspect: age differences were similar in both samples, except for the subscale PD in the patient group (partly contrary to hypothesis 3). Suffering from a rheumatic disease was related to negative perceptions with regard to the physical aspect of aging earlier in the life course. Patients in middle adulthood experienced the physical aspect of aging similar to older people without a rheumatic disease. For these patients, feeling physically old started in the middle of their life. These results were in line with assumptions and empirical results about 'accelerated aging' and 'premature aging' in patients with chronic physical conditions and disabilities (Campbell, Sheets, & Strong, 1999; Harrison et al., 2008; Sheets, 2005). Assuming that previous findings about the association between negative self-perceptions of aging, health behavior and health outcomes also hold for patients with rheumatic disease, our results pointed to an unfortunate set of experiences with aging and assumptions about the aging process in middle-aged and older patients. This mindset might operate as a cognitive bias and might, thereby, directly and

Table 4. Medians and interquartile ranges for PD, SL, and CG as measured by PEAS for the total samples and three age groups.

	Sample	Total	40–54 years	55–65 years	66–85 years	Kruskall Wallis test for age differences
PD	DAS	7.0 (5.0–8.0)[a]	6.0 (5.0–8.0)	7.0 (5.0–8.0)	7.0 (5.0–9.0)	$\chi^2 = 20.92$, $p < 0.001$
	Patients	8.0 (7.0–9.0)[a]	8.0 (7.0–9.25)	7.0 (5.75–8.25)	9.0 (6.0–9.0)	$\chi^2 = 4.63$, $p = 0.099$
SL	DAS	3.0 (1.0–4.0)[b]	2.0 (1.0–4.0)	3.0 (1.0–5.0)	3.0 (1.0–5.0)	$\chi^2 = 11.61$, $p = 0.003$
	Patients	3.0 (1.0–4.75)[b]	2.5 (1.0–4.0)	2.0 (0–4.0)	3.0 (1.0–5.0)	$\chi^2 = 6.80$, $p = 0.033$
CG	DAS	8.0 (6.0–9.0)[c]	8.0 (7.0–10.0)	8.0 (6.0–9.0)	6.0 (5.0–8.0)	$\chi^2 = 126.22$, $p < 0.001$
	Patients	7.0 (6.0–9.0)[c]	8.0 (6.0–9.0)	8.0 (7.0–9.0)	6.0 (5.0–8.75)	$\chi^2 = 10.15$, $p = 0.006$

Notes: DAS = Dutch Aging Survey.
[a]Mann-Whitney test between DAS and patients for PD ($Z = -5.97$, $p < 0.001$).
[b]Mann-Whitney test between DAS and patients for SL ($Z = -0.650$, $p = 0.516$).
[c]Mann-Whitney test between DAS and patients for CG ($Z = -0.725$, $p = 0.468$).

indirectly (through health behaviors) influence mental and physical health. Relations with the reduced survival of patients diagnosed with rheumatoid arthritis compared to the general population (Minaur, Jacoby, Cosh, Taylor, & Rasker, 2004) should be investigated from this perspective. The qualitative studies with patients (Ballantyne et al., 2007; Gignac et al., 2006; Turner et al., 2007) provided valuable insights into the relationship between perceptions of aging and medical consumption as one form of health behavior. These indicated that unfavorable beliefs with regard to treatment outcomes in older patients might lead to underuse of therapeutic possibilities.

Besides medical adherence, well-dosed physical activity is a highly important aspect of positive health behavior for patients with rheumatic diseases. In order to increase muscle strength, general fitness, and different aspects of mental health, patients with rheumatic disease are advised to integrate physical activity into their everyday life. Wurm et al. (2010) showed that positive views on aging significantly contributed to higher levels of physical activity in older adults of the general population. Further research should clarify whether this relationship also holds for patient populations. The association might be even stronger due to the concerns of some patients that physical exercise might have negative effects on their painful joints.

The causal interpretation of our results has to be proven with longitudinal data. Both samples were cross-sectional; we cannot draw conclusions on causality. For the patient sample, longitudinal follow-ups are required to confirm the predictive value of the experience of aging for health behavior and health outcomes in rheumatic disease. Some further methodological remarks also have to be made about this study. The subscale PD of the PEAS showed lower reliability in the patient group. However, a 'thinking-aloud-study' with arthritis patients indicated options for more precise wording of two items but revealed no substantial misinterpretations or difficulties in answering (Bode & Jansen, under review). Another methodological weakness might lie in the number of participants from the DAS who reported back and joint symptoms. We have decided not to exclude them from the analyses. These symptoms were self-reported with unclear validity. Neither objective medical information nor diagnoses were available. Composing a survey sample without individuals with perceived back and joint problems would, in fact, increase the differences between the samples and reduce the value of a population sample to a less representative healthy sample.

The results of various studies on the relationship of perceptions of aging with mental and physical health lead to the question of how subjective experiences of aging can be improved. To our best knowledge, psycho-educational interventions that primarily focus on the improvement of perceptions of aging are unavailable. More general aging-related programs seem to be too unspecific to change perceptions of aging. The intervention 'In anticipation of the golden years', for example, which aimed to improve proactive coping competencies in older adults, showed only small short-time effects on aging perceptions (Bode, de Ridder, Kuijer, & Bensing, 2007; Bode & van de Meer, 2006). Therefore, modules explicitly focusing on the experience of aging should be developed. They might add an important aspect to the existing self-management interventions for patients with rheumatic disease (Iverson, Hammond, & Betteridge, 2010). Psycho-educational strategies should be used to disentangle disease complaints and signs of aging as perceived by the patient. Such strategies would prevent cognitive and behavioral downward spirals and promote the use of adequate medical treatment and health behavior among older patients with rheumatic disease. Our suggestions are in line with recent observations about the potential to improve the treatment and well-being of older patients with rheumatic disease (Birrell & Felson, 2009; Schmajuk et al., 2007) and the introduction of gerontorheumatology (van Lankveld, Franssen, & Stenger, 2005; van Lankveld, Franssen, van Kessel, & van de Putte, 2004).

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